ORGAN DONATION IN THE EIGHTIES:

THE MINISTER'S TASK FORCE ON KIDNEY DONATION

Sponsored by
THE ONTARIO MINISTRY OF HEALTH

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INDEX

SECTION I: M.A. Robinette, C.R. Stiller

Introduction 1
Background to the Task Force 4
Appendix - Terms of Reference 13
Summary of Task Force Findings 14
Summary of Task Force Recommendations 24
Implementation of Recommendations 32

SECTION II: C.R. Stiller, M.A. Robinette

Conference Summation - Introduction 33
I. Public/Patient Component 37
II. Professional Component 46
III. Retrieval System Component 56
IV. Distribution Component 66

SECTION III: Subcommittee Reports

Donor Identification: C.J. Cardella, G.A. deVeber, C. Hollenberg, W.J.S. Marshall, R. Seaver, M.A. Robinette, M.C. Lindberg, C.R. Stiller 69

Donation Process: M.A. Robinette, W.J.S. Marshall, G.S. Arbus, K. Beal, R.C. Bennett, W. Brady, D.M. Harris, D. Rimstead, P. Morrin, C.R. Stiller, R. Seaver 91

Donor Transportation: M.C. Bouffard, R.G. Bennett, D.M. Harris, M.C. Lindberg, W.J.S. Marshall, D.A. Psutka, M.A. Robinette, C.R. Stiller 135

Organ Retrieval and Distribution: P.A. Keown, G.S. Arbus, R.C. Bennett, M.C. Lindberg, G.A. Posen, A.G. Shimizu, M.A. Robinette, R. Seaver, C.R. Stiller 143

Living Related Donation: C.R. Stiller, C.R. Abbott, M.C. Lindberg, D. Rimstead, M.A. Robinette, A.G. Shimizu 178

SECTION IV: Supplements

ABT Associates Research Summary: S. Corlett

- Public Attitudes to Human Organ Donation 214
- Professional and System Barriers to Organ Donation 232

Review: Emotionally Related Donors and Renal Transplantation 249
J. A. Burley
C. R. Stiller

SECTION I

INTRODUCTION

The expansion of organ transplant programs over the past decade has resulted in a realization of the age-old dream of replacing diseased parts with healthy ones. There is perhaps no better example of this than patients developing kidney failure. The discovery of the artificial kidney machine saved such patients from certain death. However, regular dialysis treatments are time-consuming and expensive, and necessitate strict fluid and dietary limitations. Such patients are chronically fatigued and often feel unwell. A successful transplant restores the recipient's sense of well-being and former health and permits a return to activities and work formerly inhibited by kidney failure. Thus, transplantation affords a considerable financial saving to society by eliminating the need for on-going dialysis and by returning the individual to the work force.

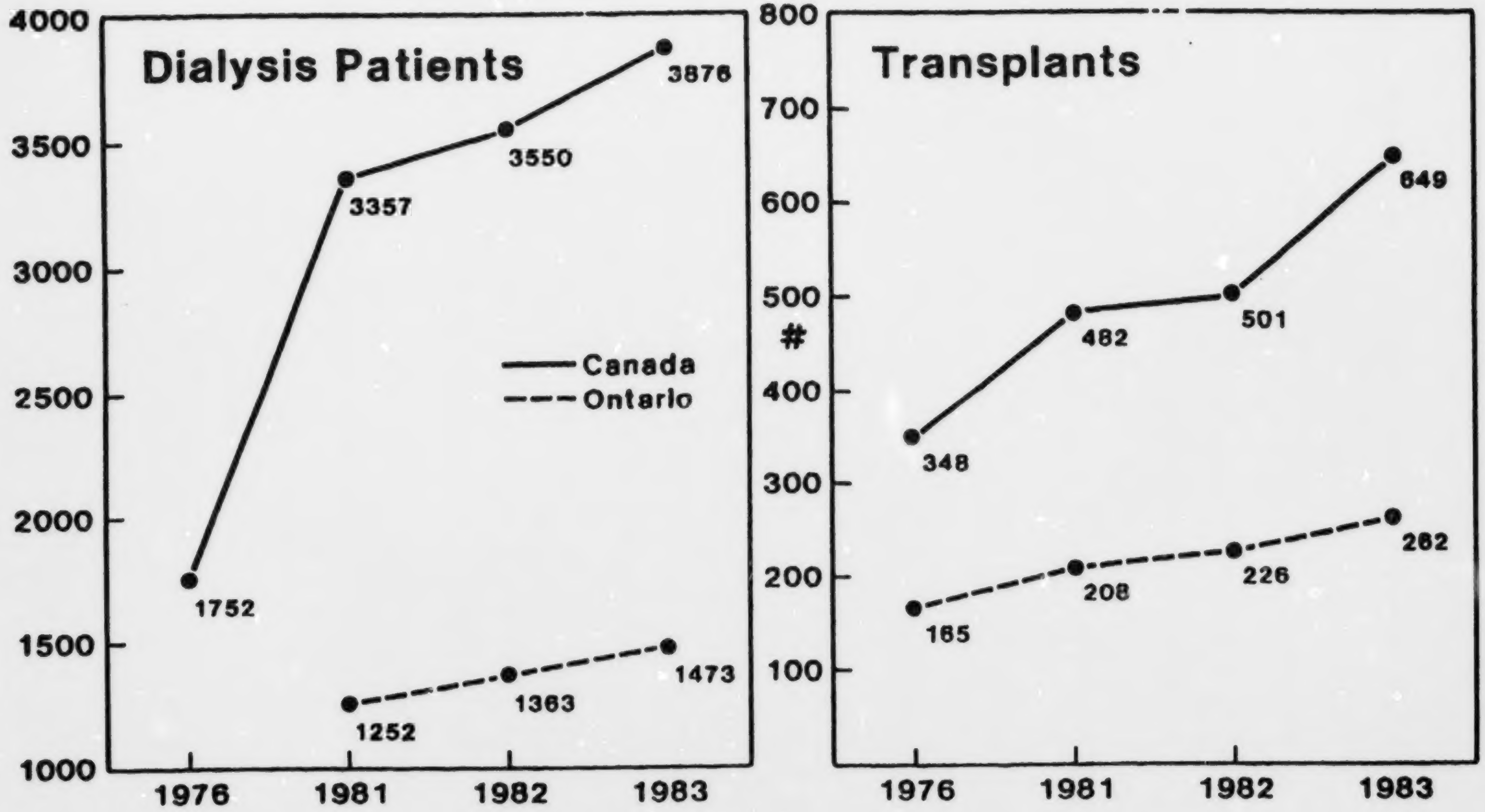
Between 1976 and 1981, the number of dialysis patients in Canada doubled and since then there has been a continued steady growth; approximately 40% of all patients are Ontario residents (Figure 1). Considered largely experimental only 25 years ago, today renal transplantation is the recommended form of therapy for the majority of patients developing chronic renal failure. However, transplantation has not met this demand mainly because there has been an insufficient supply of donated kidneys.

Approximately 20% of patients requiring a kidney transplant have a suitable relative (parent, sibling or child) willing to donate their kidney. When there is a good match between a related donor and recipient, excellent results are achieved with over 90% of grafts functioning at the end of two years and beyond. Unfortunately, the majority of renal failure patients have no such well-matched relative willing to donate, and so they must wait for a cadaveric donor. The waiting period often extends for several months and sometimes for a few years. Graft survival results from unrelated donors are presently 70-80% at the end of two years.[1] Because the supply of cadaveric donors is currently inadequate to meet the needs of those waiting for a transplant, living non-related donors (e.g. a spouse or a friend) are being considered.

Pre-emptive transplantation, circumventing the need for entering the dialysis program altogether, is recommended for diabetics in order to arrest the visual disturbances which cause blindness. Recently, other patients developing renal failure are being offered transplantation prior to dialysis in order to avoid spending a period of time on the artificial kidney and thus produce further cost saving. However, once again the inadequate supply of organs has exerted its effect such that pre-emptive transplantation is a rare occurrence at the present time.

Fig. 1

DIALYSIS AND TRANSPLANT GROWTH 1976-1983



BACKGROUND OF THE TASK FORCE: Health Care and Financial Implications

The limiting factor in transplantation has been the supply of organ donors and in 1976 the Metro Organ Retrieval and Exchange Program was established to improve the organ donation rate and to ensure that all donated organs were used. By 1978 all transplant centres in Ontario (Table 1) had joined and this has now been reorganized as the Multiple Organ Retrieval and Exchange Program (M.O.R.E.). After only two years, the supply of kidneys had increased significantly and the donation rate has grown each year by approximately 8% (Figure 2). In 1983 Ontario's transplantation rate per million population was 29.7, above the Canadian average of 26.1 and the American rate of 20.6.[2]

The cost of treatment for end-stage renal disease is not easily grasped by the general public. Each patient experiencing kidney failure in Canada is offered chronic dialysis treatment and the most commonly used method, that of haemodialysis, costs $40,000 per patient per year (1984 dollars). There is an incidence of 60 per million per year new patients developing chronic renal disease with an average age of 50[2] and projected life expectancy of another 20 years. At the present time there are 156 per million population currently on dialysis. With a provincial transplantation rate of only 29 per million per year, the effect on the rising cost of health care can be seen. Given these parameters, the 1984 cost of treating end-stage renal disease in Ontario was approximately $61 million (which represented 0.7% of the total 1984 health care budget.)

TABLE I

REGIONAL CENTERS IN M.O.R.E.

Centers	Area Covered
St. Joseph's Hospital, Hamilton	Hamilton, Kitchener-Waterloo and Niagara Peninsula
Kingston General Hospital, Kingston	Kingston and Eastern Ontario
University Hospital, London	London, Sudbury and South Western Ontario
Ottawa Civic Hospital	Ottawa & Eastern Ontario
Ottawa General Hospital	
Toronto General Hospital	Toronto, Central and Northern Ontario
Toronto Western Hospital	
St. Michael's Hospital	
Hospital for Sick Children	

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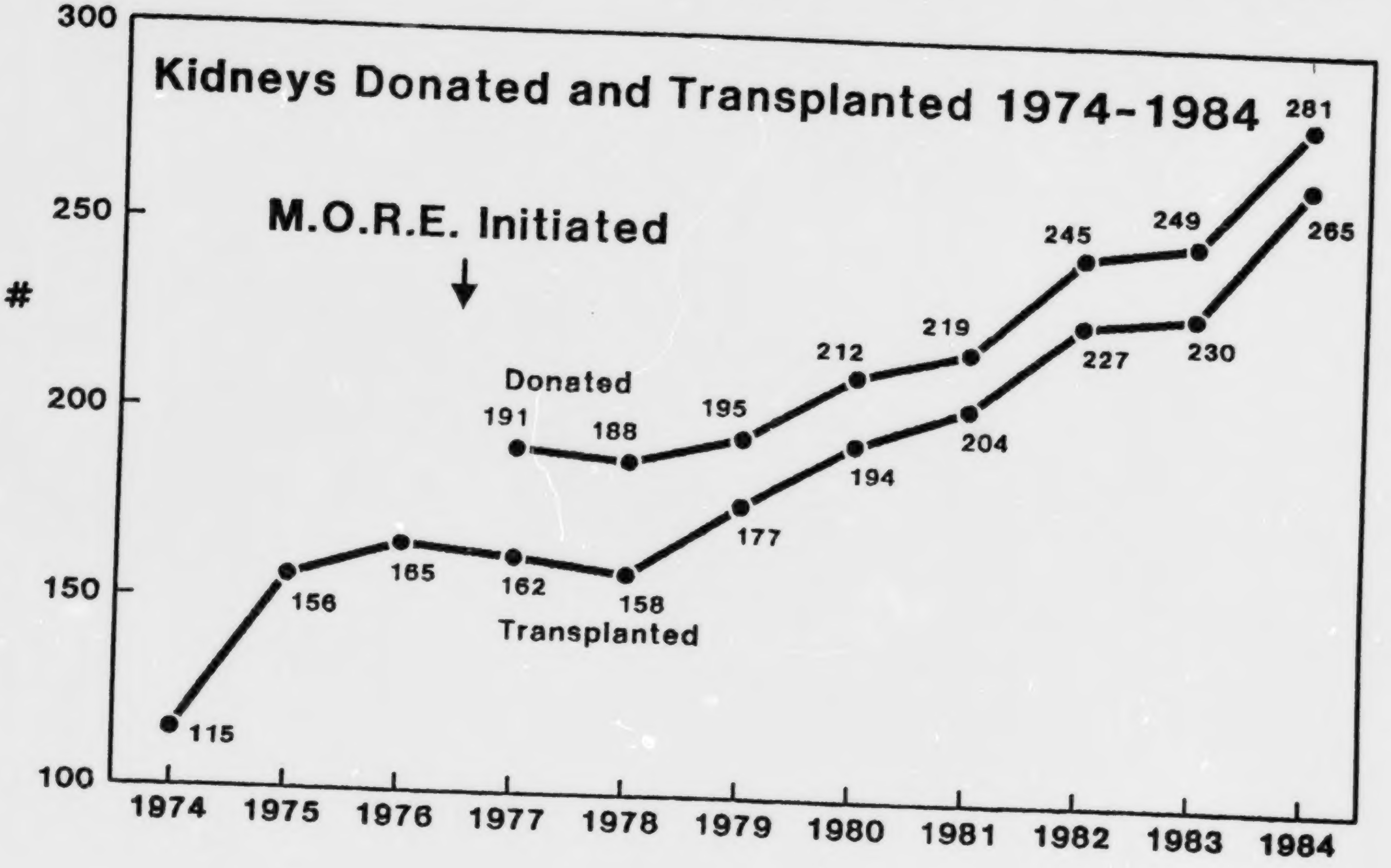
Fig.2

MULTIPLE ORGAN RETRIEVAL AND EXCHANGE

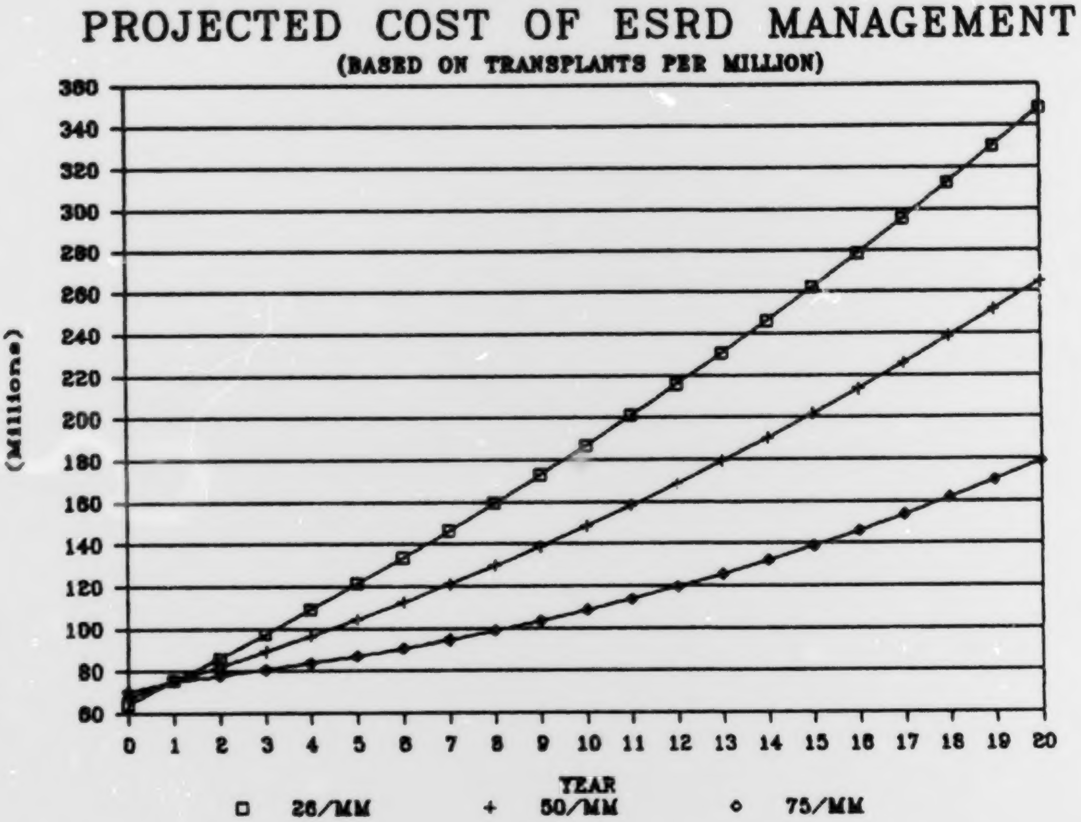


With reference to Figure 3a and the listed assumptions, the cost to the Ontario government will rise to over $180 million by 1994 and almost $350 million in the year 2004. This is stated in current 1984 dollars and makes no allowance for inflation or increasing costs above the inflation rate. This increasing cost will not be significantly altered by a slight improvement in the success rate of transplantation. Rather, it is by a doubling of the number of donors that a cost saving of $0.8 billion can be achieved over a 20-year period with a net saving as early as Year 4 of $5 million. However, the costs continue to rise even with a doubling of the number of transplants to the point of costing approximately $150 million for the end-stage renal disease program in 1994 and over $260 million in the year 2004. Assuming no improvement in graft survival we would need to triple the number of transplantable organs to match the incoming population. With a tripling of the transplantation rate, the rate of growth is slowed considerably from the current cost of $61 million to a cost of $110 million in 1994, and $180 million in the year 2004 (compared to $350 million projected with the current rate). Thus a cost savings of $1.7 billion would occur over 20 years. (Re: Figure 3b)

The Task Force, in considering the appropriation of tax dollars and recognizing that the recommendations of this Task Force will cost money, has looked carefully at the potential to increase the transplantation rate and has attempted to balance monetary savings with the financial requirements for implementation of programs. There have been few examples in modern medicine where the direct application of health care dollars can result in such significant health care cost savings as exists in this area but it must be understood that this cost saving occurs primarily with time and its effect is not immediate.

On the contrary, it is evident that a deficit of $4.8 million would occur in 1985 with the injection of $5 million (the estimated cost of the recommendations of the Task Force) and a doubling of the number of transplants as the projected cost in Year 1 would be reduced from $75,333,000 to $75,159,000. By Year 2 the cost would be $82 million as opposed to $86 million with a gross saving of $4 million. However, with a $4.8 million deficit (Year 1) and the injection of $5 million for maintenance of recommendations, Year 2 would represent a $5.8 million deficit. By Year 3 the cost would be reduced from $97.3 million to $89.1 million with a gross saving of $8.2 million. The net saving would be $2.4 million once the cumulative deficit ($5.8 million) has been removed. With the injection of another $5 million, there would be a $2.5 million deficit. It is only by Year 4 that this deficit would be obliterated and a $5 million net saving would occur. These figures do not take into account the lives saved from application of transplantation in non-renal organ transplants (e.g. livers, hearts, heart-lung, lung and pancreas). Thus, it is apparent that considerable savings will occur over time with doubling ($0.8 billion) and tripling ($1.7 billion) of the transplantation rate.

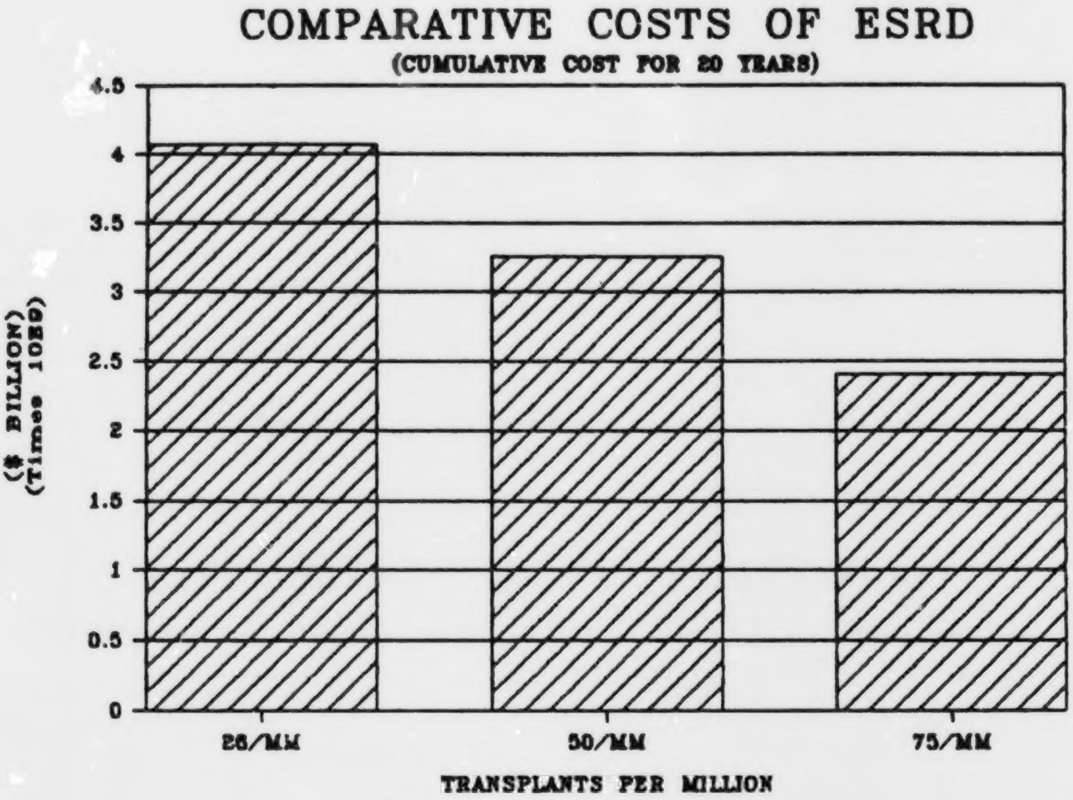
FIGURE 3a



ASSUME:

1. Present rate of transplantation (donation) 26/mm/yr
(doubling) 50/mm/yr
(tripling) 75/mm/yr
2. Annual mortality rate of 9.0% in years 1,2
4.0% thereafter (dialysis pt.)
3. Annual mortality rate of 6.0% in year 1
4.0% in year 2
1.5% thereafter (transplant pt.)
4. Rejection (graft loss; pt. returns to dialysis) rate of 20.0% in year 1
3.0% in years 2,3
1.5% thereafter
5. Costs: Dialysis $32,500 Blend of haemodialysis ($40,000) and home dialysis/self-care ($25,000)
Transplant $23,000
Post-op Treatment $23,000 in year 1
$ 5,000 thereafter
Rejection $16,000

FIGURE 3b


COMPARATIVE COSTS OF ESRD
(CUMULATIVE COST FOR 20 YEARS)
($ BILLION)
(Times 10E9)
4.5
4
3.5
3
2.5
2
1.5
1
0.5
0
25/MM
50/MM
75/MM
TRANSPLANTS PER MILLION

It was with recognition of these issues and in the face of an increasingly inadequate supply of donated kidneys that the Task Force conducted its work. It has done so with a sense of urgency and the belief that its recommendations can make a substantial impact on this escalating crisis. Given that there was a potential to improve the organ donation rate, and based on the provided terms of reference (re: Appendix), the objectives of the Task Force were:

1. To document that there was in fact a potential to increase the supply.

2. To identify the existing barriers to organ donation.

3. To recommend changes to overcome the barriers in order to effect an increase in the kidney donation and transplantation rates.

Although the Task Force was directed to study kidney donations rather than all organ donations, it was realized that any increase in supply of organ donors would also benefit the non-renal transplant programs.

The Task Force was divided into the following subcommittees, each of which studied their assigned areas in order to document the inhibiting factors and recommend corrective measures:

1. Donor Identification Committee
2. Donation Process Committee
3. Transportation Committee
4. Organ Retrieval and Distribution Committee
5. Living Donor Committee

The detailed reports of the subcommittees were presented to a symposium on organ donation organized by the Task Force and the Ministry of Health. The findings and recommendations of the reports were reviewed and discussed by an international group of experts in the field of organ donation, and workshops provided an opportunity for the symposium participants to contribute to the final recommendations which are presented herein.

REFERENCES

1. Centre for Transplant Studies, Canadian Transplant Study Group. London Ont 1984

2. Kidney Foundation of Canada, Statistics Canada, Health and Welfare Canada: Canadian Renal Failure Register. 1983 Report

Ontario

Ministry Ministère
of de
Health la Santé

JUNE, 1983

TASK FORCE TO INVESTIGATE AND DEVELOP METHODS OF INCREASING KIDNEY DONATIONS FOR TRANSPLANTATION

Terms of Reference

The Task Force shall advise the Ministry of Health on:

1. What are the current barriers to organ donation and transplantation.
2. Ways and means to facilitate organ donation such as -
   a) donor awareness;
   b) living related donor encouragement and incentive;
   c) police and emergency personnel;
   d) computerized registry of donor wishes;
   e) physician encouragement;
   f) emergency department staff;
   g) I.C.U./C.C.U. staff;
   h) clergy/hospital chaplin;
   i) all aspects of transportation.
3. Methods of enhancing public awareness to increase organ donations:
   a) a short-term advertising program and/or pilot projects to raise public awareness of the importance of kidney donations.
   b) a long-term plan to ensure continued public participation in donation of organs.

SUMMARY OF TASK FORCE FINDINGS

1) EVIDENCE THAT A POTENTIAL EXISTS TO IMPROVE THE DONOR SUPPLY

Using death statistics from Ontario hospitals in 1981 and 1982, a large difference was found to exist between the number of potential organ donors and those converted to actual donors. For instance, in 1981, of 34,694 hospital deaths in Ontario, 1,179 were considered potentially suitable as organ donors (147 per million population) and yet, of these only 110 became actual donors (14 per million population). Eighty percent of these potential donors died in group 01 or 02 hospitals (OCATH (Ontario Council of Administrators of Teaching Hospitals) and Centers having 400 or more beds).

The potential for significantly increasing the supply of donors was also supported by detailed death audits carried out in six hospitals (three teaching centers and three primary and secondary care hospitals). This analysis revealed that the number of potential organ donors not converted into actual donors varied between 45% and 80% in 1980 to 1982.

An analysis of fatality rates from car accidents (the most common donor source in M.O.R.E.) revealed that had all those dying in hospital following admission from a car accident (297 in 1981) become organ donors, 594 kidneys would have been available for transplantation. However, in 1981 there were only 219 kidneys donated from all sources.

2) EVIDENCE THAT BARRIERS TO ORGAN DONATION EXIST WITHIN HOSPITALS

Health care professionals (doctors, nurses, hospital chaplains and administrators) in 118 Ontario Hospitals with Intensive Care Units were surveyed concerning their policies and attitudes towards organ donation. Administrative responses indicated that less than half of the hospitals had an organ donor policy and actively promoted organ donation. Not surprisingly, the number who did promote organ donation was markedly larger in those hospitals with renal transplantation and/or dialysis programs, being 93% in these hospitals compared to 36% in the remaining hospitals.

Reasons for not having a policy promoting organ donation included a lack of interest by the medical staff (48%) or hospital board (39%) and a perception that organ donors were an infrequent occurrence within their particular institution (68%).

It was encouraging to note that 85% felt that their hospital would refer potential donors if asked and 63% would also refer donors if changes were made to hospital policy and financial reimbursement to the hospital occurred.

3). EVIDENCE THAT BARRIERS TO ORGAN DONATION EXIST AMONG THE PUBLIC

The public's attitude towards organ donation was assessed by reviewing previous surveys and by conducting new studies on behalf of the Task Force. Focus groups revealed six major reasons for not signing an organ donor card:

a) Concern about hastiness of declaration of brain death and organ removal, and a feeling that the family's expression of grief may be interfered with.

b) Mutilation.

c) Fatalism and superstition.

d) Religious attitudes

e) Age (many people felt that they or their relatives would not be suitable donors unless they were very young).

f) "I just never thought of it".

Also found was uniform opposition to presumed consent, mandatory donation, and to any form of commerce in organ donation. Participants in these focus groups felt that there was a need for ongoing public education concerning the successes of transplantation, the need for organ donors and that relatives should not be able to countermand the signed donor card.

A poll conducted in Ontario in early 1984 on behalf of the Task Force revealed that 72% of approximately 1,000 respondents had not signed their driver's licence. Motivating people to sign seemed to be important because it was found that although 88% would respect the wishes of a relative and donate their kidneys upon death, only 63% were in favour of donating their own kidneys. This discrepancy between the willingness to donate one's own organs and one's relatives' organs was also found in a poll conducted in the United States in 1983 by the Gallup Organization on behalf of the National Kidney Foundation. Seventy-two percent supported donating kidneys of a relative whereas only 24% were in favour of donating their own kidneys after death.

These findings would suggest that public resistance to organ donation is low and accounts for a small percentage of the failure to obtain consent; nevertheless, 80-90% of health care professionals in transplant and dialysis centers have at some time experienced consent refusal for organ donation. These same nurses and doctors identified "relatives" as being a major barrier to organ donation.

4). EVIDENCE FOR MEDICAL BARRIERS TO ORGAN DONATION

The medical barriers to organ donation were studied by surveying doctors (including interns and residents), nurses and chaplains working in 118 Ontario Hospitals with Intensive Care Units. Also, all Neurosurgeons and Neurologists in the province were included in the poll. The barriers found were:

a) Failure to Identify a Suitable Donor:

In transplant and dialysis centers respectively, the following professionals were considered to be most likely to identify a donor and initiate the donation process: resident (80%/57%), attending M.D.s (78%/54%) and nurses (50%/51%).

In spite of the fact that the majority of respondents answered specific questions relating to the suitability of potential donors for organ donation correctly, there was a significant number of surprisingly incorrect answers. (That is, patients identified as non-suitable who were considered suitable by the Task Force)

b) Failure to Initiate the Donation Process:

(i) Policy and Procedure:

- In hospitals with a transplant or dialysis program, only 65% were aware of a telephone number to call for advice or assistance with the nursing supervisor being the individual (46%) and the M.O.R.E. program being the service (48%) most likely to be contacted. Transplant coordinators were identified to provide assistance with donation (approximately 80%) in transplant hospitals; whereas in non-transplant centers without dialysis units, the urologist was seen to fill this role by 75% of the respondents.
- Lack of coordination, no firm guidelines and no clear lines of responsibility were seen as the major inhibiting factors in initiating the donation process with 75% or more of respondents in all hospitals. Three-quarters also said that the time demand of the donation process was a significant barrier.

Two-thirds of doctors and 82% of nurses in non-transplant hospitals without a dialysis unit stated that a significant barrier seemed to be a lack of an in-hospital team or individual assigned to the donation process.

- The majority of respondents (85% to 95% in "other" hospitals) recognized that a lack of familiarity with the donation process was a significant barrier, and approximately 90% identified the need for more lectures, written information and in-service training.

(ii) Financial and Legal:

- Financial concerns were identified in hospitals without a transplant or dialysis unit, with the donation process possibly adding to their ICU budget. The lack of adequate remuneration to physicians involved in the donation process was stated as a barrier with 25% of ICU M.D.s in transplant and dialysis centers; however, this number increased to approximately 50% of physicians in other centers.

- A perception that legal factors were a potential problem seemed to posc some barrier to initiating the donation process with over 70% of physicians (but only 36% of Neurosurgeons) and with more than 80% of nurses.

(iii) Personal:

- Personal feelings towards organ donation was felt to be a barrier with 50% of all nurses, interns and residents, and with about 45% of ICU and other M.D.s in the transplant centers.

- Approximately 50% of doctors and nurses felt inhibited in initiating the donation process by "bothering" a grieving family for consent.

- Although over 90% of respondents recognized the need for more donors and realized that health care professionals had a role in the donation process, a significantly lower percentage of ICU MDs (71%), other MDs (72%) and Neurosurgeons (44%) in all centers responded that they would in fact initiate or would like to become involved in the donation process.

5). EVIDENCE FOR BARRIERS TO ORGAN DONATION AS A RESULT OF TRANSPORTATION FACTORS

An assessment was made of the existing regional trauma centers and the important role of the Ontario Air Ambulance System in providing rapid transport of stabilized patients to the trauma centers. By providing this treatment facility to as many as possible, not only was it noted that there will continue to be a decline in trauma-related mortality, but inevitable treatment failures will be more readily available for organ donation.

Costs of transportation involved in organ retrieval and transplantation were identified including:

a) The transportation of a donor from either within or out of Ontario to the recipient center.
b) The prompt return of the donor's body to the funeral home for preparation for burial.
c) The transportation of provincial retrieval teams to the donor center for removal of the organs.
d) Tissue typing expenses incurred outside the Province of Ontario to determine the suitability of a patient outside the Province as an organ donor for an Ontario recipient.
e) Travel and other costs for out of province kidneys that are on perfusion and require a perfusionist travelling to the transplant centre.
f) Transportation of a potential recipient to the transplant center for work-up and for the eventual transplant procedure.
g) Transportation of living related donors to and from the transplant center for donor nephrectomy.

6). EVIDENCE FOR BARRIERS TU ORGAN DONATION AS A RESULT OF DISTRIBUTION FACTORS

a) Technical aspects of organ distribution were reviewed including forms of organ preservation (cold storage vs continuous perfusion) and organ transportation. Although the published experience suggests no difference in graft or patient survival between the two forms of organ preservation, a recent prospective controlled comparison study conducted by M.O.R.E. revealed a significantly better initial function of kidneys preserved on machine. Although machine preservation is more expensive ($808.00 vs $113.00), the extra cost may be off-set by a lower requirement for dialysis and a shorter period in hospital for patients receiving kidneys which begin functioning immediately. More research is required in this area.

Four methods of transportation of organs currently used in Ontario were assessed. Kidneys and tissue samples are distributed between centers most often by police transport and occasionally by the M.O.R.E. van. The M.O.R.E. van is the primary mode of transportation in Toronto and between Toronto and Hamilton and occasionally Kingston and London. Transportation beyond Southern Ontario and out of the Province is arranged by air. Although transportation facilities are not lacking, inappropriate methods, a lack of system centralization and inadequate policy regarding financial reimbursement by government to retrieval programs have been noted.

b) Immunological considerations in organ distribution addressed by the Task Force were the pre-sensitized patient and the effects of histocompatibility matching. The current M.O.R.E. protocol was reviewed which rates as a priority highly pre-sensitized patients (greater than 75% reactivity against a panel of donors) who are crossmatched negative for a particular kidney. Graft survival is much lower (50-30%) among such patients receiving a second or subsequent transplant, and it is only by organ sharing that such patients ever have a hope of receiving a transplant. Immunological considerations were not perceived as a barrier at the present time but could become so without a centralized system. With such a system, a greater pool of potential donors would enhance the chances of presensitized patients receiving a successful transplant.

Recent data was reviewed concerning the influence of histocompatibility matching which suggested enhanced graft survival among patients receiving kidneys matched at the DR locus or when no detectable mismatch existed at these loci. Further research is needed in this area.

c) The economics and efficiency of organ retrieval in Ontario were assessed. Data from Ontario were compared to eleven Canadian transplant centres and twenty-three major American transplant programs. From the data analysed, Ontario's retrieval system was found to be highly cost effective. With a transplant rate of 29 per million population and a utilization rate of over 90%, Ontario was noted to also have a highly efficient retrieval system. However, deficiencies have been noted and recommendations have been proposed to improve the system.

SUMMARY OF TASK FORCE RECOMMENDATIONS

1. RELATED TO HOSPITAL BARRIERS

a) That the Board of Directors of each acute care hospital in Ontario be encouraged to establish policies which promote and facilitate organ donation in their hospital.

b) That each hospital administration establish an Organ Donation Committee to implement policies and procedures which affect the supply of organs for transplantation using guidelines developed by the Task Force to:

(i) Designate a team or individual to act as an Organ Donation Coordinator overseeing the stages of the donation process including donor maintenance, assistance with relatives, and interaction with the provincial organ retrieval program (M.O.R.E.) and the regional retrieval programs.

(ii) Ensure regular in-service training and education.

(iii) Apply the criteria to be used for the identification of potential donors which can also be used for auditing the effectiveness of such identification.

(iv) Consider employing a system of "recorded consideration" of donation request by the attending physician or his/her designate to record, on the hospital chart, the fact that consideration had been given to request for organ donation. This recording would be required in every hospital death in which the patient fulfilled the established donor criteria. The record would state the outcome of the request or the reason why a request was not made.

c) That appropriate recognition of hospital costs incurred in organ procurement and donor care be given by the Ministry and out-of-province insuring agencies.

d) That a means be established to provide an accurate audit of organ retrieval and inter-institutional organ exchange.

2. RELATED TO MEDICAL BARRIERS

a) That a set of guidelines be provided to each hospital for consideration and adoption into its policy and procedures manual. Topics to be covered would include:

- consent forms and methods of obtaining consent
- declaration of brain death
- optimal donor maintenance
- transportation of potential organ donors from centre to centre
- provision of temporary operating privileges for renal and non-renal retrieval teams from other hospitals.

b) That health care professional organizations be encouraged to include in their continuing education programs information concerning transplantation and the need for donor organs. Materials for this should be developed by the Ministry in conjunction with M.O.R.E. and the regional retrieval programs.

c) That Faculties of Medicine in the Province of Ontario be approached and encouraged to include in their curriculum programs information outlining the physician's responsibility as an initiator and participant in the organ donation process.

d) That suitably qualified physicians on hospital staff be identified to assist in the declaration of brain death.

e) That appropriate remuneration be given to physicians participating in the activities of organ procurement.

f) That, in conjunction with medical and nursing staff, hospital chaplaincy and social work services be utilized as integral participants in the donation process with particular responsibility for ministering to the needs of the donor and the donor's family.

g) That discussions be held with the medical, hospital, and nursing associations to establish a professional medical consensus regarding the concept of "recorded consideration" of donation request by attending physician or his/her designate.

3. RELATED TO PUBLIC BARRIERS

a) That an imaginative, ongoing public information program is required to focus on the urgent need for donor organs, the successes of transplantation and the positive effects of transplantation, both medical and economic.

b) That the public be urged to make a commitment by signing drivers' licences and other organ donor cards.

c) That a professional campaign be used in all media to stimulate public and professional support for transplantation and organ donation.

d) That market research be employed as follow-up to measure the effectiveness of this campaign.

e) That the M.O.R.E. toll-free number (1-800-387-LIFE) be widely publicized and continue to provide the public with further information concerning transplantation and organ donation.

f) That research be conducted regarding a universal record of consent and the best means of recording post-mortem donation wishes, including the concept of a central registry.

4. RELATED TO TRANSPORTATION BARRIERS

a) That coverage be provided for the following:

- recipient transportation costs and, in the case of children, parent/guardian transportation costs;

- living related donor transportation (in and out of province);

- the cost and means of transporting a cadaveric donor body to the recipient centre (by air ambulance if available) and back home for burial preparation (This should include both out-of-province and Ontario donors.);

- the transportation costs incurred by the designated hospital Organ Retrieval Teams.

5. RELATED TO THE STRUCTURE OF THE PROVINCIAL ORGAN RETRIEVAL PROGRAM

a) That the provincial Multiple Organ Retrieval and Exchange Program (M.O.R.E.) be expanded and suitably funded by the Government of Ontario in order to continue to function as the province-wide body responsible for coordinating retrieval and distribution of all organs, organizing ongoing public and medical education, reviewing and recommending technical standards, and maintaining all organ retrieval and transplant data for the purpose of periodic analyses and reports. This provincial program should be a democratic and fully participatory group of the renal programs utilizing the present and potential strengths of all the participating centres.

b) That a Canadian Organ Retrieval and Exchange program (C.O.R.E.) be established to interact wih M.O.R.E. and other provincial Organ Retrieval Programs. C.O.R.E. should also facilitate national collaboration for public and professional awareness programs and interact with the Royal College of Physicians and Surgeons and the Canadian Hospital Association. (Figure 4)

c) That a 24-hour toll-free number (1-800-387-MORE) continue to provide ready access to the central program for provincial health care professionals or by programs outside Ontario offering organs to M.O.R.E.

d) That the regional programs in Hamilton, Kingston, London, Ottawa and Toronto be suitably funded in order that they provide maximum efficiency for regional organ procurement. Necessary expenses include personnel to coordinate organ donation and to interact with the central program, regional public relation costs, and funds for local computerization.

Guidelines for the requirements of the different Regional Retrieval Programs should be drawn up by the Working Party and agreed to by government and the participants. The staffing should include, where appropriate, a Director, Transplant Coordinator, Assistant Transplant Coordinators depending on the size of the program and, if extra-renal transplants are performed, a mobile Donor Retrieval Technician.

FIGURE 4 THE ORGAN RETRIEVAL SYSTEM IN ONTARIO:

CANADIAN ORGAN RETRIEVAL & EXCHANGE:
C.O.R.E. (CANADA)

↕

MULTIPLE ORGAN RETRIEVAL & EXCHANGE:
M.O.R.E. (ONTARIO)

↕

REGIONAL ORGAN RETRIEVAL PROGRAM:
HAMILTON, KINGSTON, OTTAWA, LONDON, TORONTO

↕

PARTICIPATING ORGAN DONOR CENTRES:
ALL HOSPITALS WITH I.C.U.'s

The availability of a transplant retrieval team, reliable tissue typing and cross-match facilities, and economical air and ground transportation should be part of the guidelines defining the constitution of a Regional Retrieval Program. These guidelines have to reflect the different requirements for a single transplant centre retrieval program and the multiple transplant centre programs such as in London and Toronto. Each hospital in the province should be assigned to, and identified with, its regional program in order to ensure active participation.

6. RELATED TO LIVING DONOR

a) That appropriate educational material be prepared which will inform patients and their families of the potential for living related kidney donation.

b) That any prospective living related donor be evaluated and informed of all details by an independent physician.

c) That full reimbursement of all direct costs associated with organ donation, including transportation, be provided.

d) That a study of the potential for the "emotionally related donor" be carried out. Individuals should be able to act as emotionally related donors but only after extensive determination of medical and psychiatric suitability.

IMPLEMENTATION OF RECOMMENDATIONS

1. a) That a working party be established under the direction of the Task Force in order to execute the recommendations of the Task Force and to report back on a timely basis.

Using the preceding recommendations, the Working Party should:

(1) Formulate guidelines and protocols.
(2) Indicate the need for legislative changes.
(3) Generate materials for public and professional awareness programs.
(4) Establish collaborative links with appropriate professional organizations.
(5) Initiate research concerning the impact of the recommendations.

b) That the accepted recommendations be applied simultaneously, recognizing that failure to relieve a single obstruction prevents any benefits from the removal of other barriers.

SECTION II:

TRANSPLANTATION IN THE 80's - A BLUEPRINT FOR SUCCESS

SUMMATION OF THE CONFERENCE

INTRODUCTION

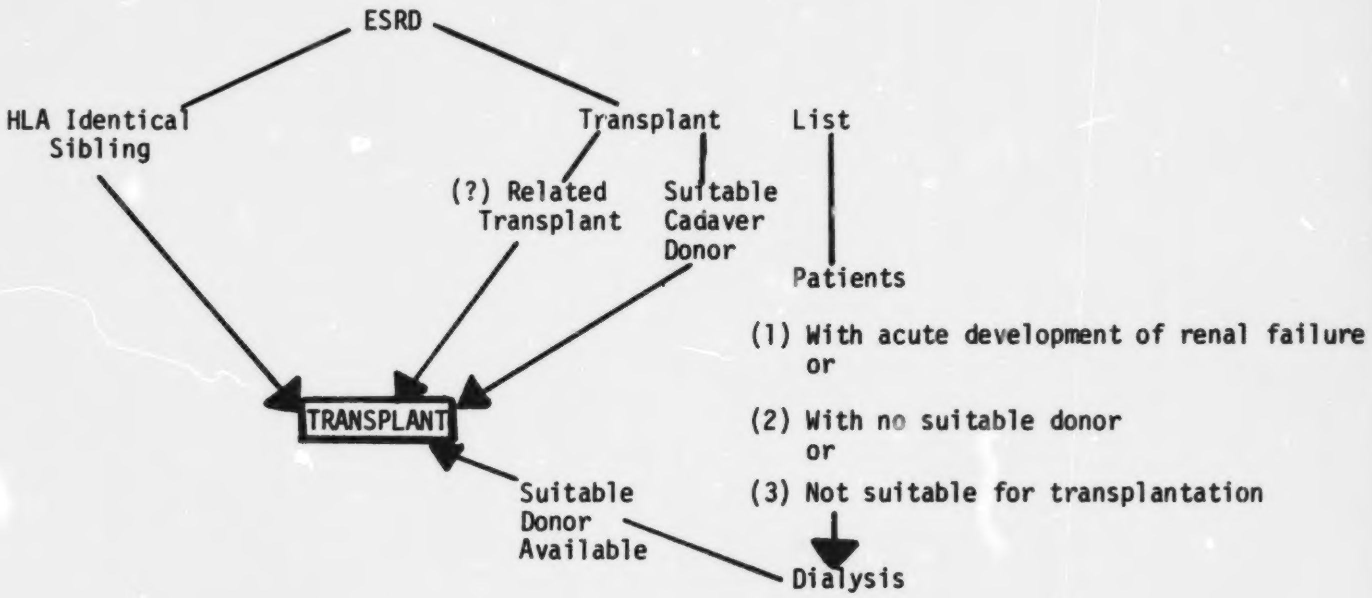
This conference has brought together the members of the Task Force and a wide representation of the public and professionals who have expressed concern for, or participated with, organ procurement and transplantation. Several factors have been responsible for the lively productive discussions this week, and we express gratitude to all of you including the tireless work of the committees, the discipline and diligence of the Chairpersons, the loyalty and creativity of the members of the Ministry of Health, and the genuine interest of the public. The result has been a consensus regarding the type of system and changes that are necessary to enhance organ donation and thereby increase the number of successful transplants.

The Task Force was formed to specifically address itself to kidney donation but it became apparent, and has been recognized by the Government, that organ donation in a generic sense is very important as we anticipate greater application of all organ and tissue transplantation in this country. Nevertheless, the primary focus with respect to need was that of increasing kidney donations. If one accepts the fact that the optimal treatment for end-stage renal failure in this country is transplantation, and that dialysis as a form of treatment is utilized when an organ transplant is not feasible or presents too great a risk, then the future management of end-stage renal failure can be as represented in the attached figure (Figure 1). The incidence of end-stage renal failure in this country is approximately 60 per million population per year. In addition, there are about 14 per million per year requiring retransplantation, either acutely or chronically. With a provincial population of 9 million, this represents more than 600 patients who might benefit from transplantation each year. In practice, only about 400 of those patients would be transplantable for one reason or another. Therefore, approximately 400 new transplantable kidneys each year would meet our requirement. Instead, we receive only about half of this number, and that does not take into account the large backlog of patients who are transplantable but presently are not on a transplant list because they wish to remain on dialysis, or do not have any reasonable hope of receiving a transplant.

The implication to patients and the health care system in Ontario of primary management of end-stage renal failure by transplantation is dramatic and convincing with respect to cost effectiveness. Ignoring known institutional costs for each patient removed from an inpatient hospital dialysis unit by a successful transplant (using projected inflation rate of 7%), an approximate cost saving of one million dollars per patient occurs over twenty years. Although such an estimate is the

FIGURE 1

FUTURE MANAGEMENT OF ESRD


ESRD
HLA Identical Sibling
Transplant
List
(?) Related Transplant
Suitable Cadaver Donor
Patients
(1) With acute development of renal failure
or
(2) With no suitable donor
or
(3) Not suitable for transplantation
TRANSPLANT
Suitable Donor Available
Dialysis

extreme of the equation, where high cost institutional dialysis is replaced with a low cost successful transplant, it is within that configuration that one should view the financial impact of transplantation. Since the goal is to obtain successful long-term graft survival, it is precisely such a long-term view of the potential savings that helps focus our attention and design remedial action. The short-term costs of transplantation equate or, indeed, may exceed those of dialysis in the stable patient. However, it is not the short-term view that motivates Government and the profession to move towards transplantation as the primary treatment for end-stage renal failure. Rather, it is the overwhelming benefit to the patient's lifestyle, feeling of health, rehabilitation and the economic savings of a successful transplant that motivate the design of a system in which the greatest number of kidney transplants are accomplished with the least amount of kidney rejection. As well, pre-emptive (prior to needing dialysis) transplantation may be possible in order to prevent disability and produce further cost saving.

The areas where barriers to organ donation might occur that were initially recognized by the Task Force included: (1) Donor Identification; (2) Donor and Donor Organ Transportation; (3) Obtaining of Consent including: (a) patient barriers, and (b) professional barriers; (4) Organ Retrieval and Exchange, and; (5) Living Donation Barriers. Reports of the deliberations of these committees are included in the Proceedings and the discussions resulted in the conclusion that a successful system has certain requisite components (Table 1). These components include: (1) an educated public, (2) an educated and committed profession, (3) a visible, easily verifiable and accessible retrieval system, and (4) an equitable distribution system. A discussion of the components and their implementation are the subject of this summation.

COMPONENTS OF PROPOSED SYSTEM

I. Educated Public and Patients

The educated public or patient population is one in which: (a) the benefits of transplantation are understood; (b) the need of organs for transplant recipients is appreciated; (c) the fears of premature donation or removal of organs prior to the diagnosis of brain death are completely allayed, and; (d) premortem wishes, with respect to the post-mortem disposal of organs, have been communicated verbally or recorded in some way.

- The benefits of transplantation are recorded in the scientific literature at the present time but are generally unknown to the public. In fact, the majority of patients who receive a transplant are rehabilitated to lead a completely normal life. The beneficial results of transplantation far exceed that of treatment for cancer and many other disabling diseases.

TABLE 1

COMPONENTS OF PROPOSED SYSTEM

EDUCATED PUBLIC AND PATIENT POPULATION

EDUCATED AND COMMITTED PROFESSION

VISIBLE AND EASILY ACCESSED RETRIEVAL SYSTEM

EQUITABLE DISTRIBUTION

- In the area of kidney transplantation, the exact number of organs required is not completely known but current supply is less than a third of the actual need. Although the shortage of adult hearts and livers is not as critical at the present time, paediatric livers and heart-lung organs require an enormous increase in the number of suitable donors in order to meet the present and projected needs.

- The film "Coma", and other similar popular productions, have raised fears of premature removal of organs prior to the actual death of the donor. The criteria for the diagnosis of brain death are not only definitive but should be well understood in the centres in which this procedure is being performed. As well, the verification that is required when a patient is referred to a transplant centre adds further assurance in that regard. Such safeguards must become apparent to the public in order for them to understand the precision with which the diagnosis of brain death is established, as well as the type of surveillance inherent in the medical audit system that would not allow errors of this magnitude to occur.

- The ideal situation, in which the public is fully informed, would be one in which a process by which the individual can record his or her premortem wishes is fully operative and successful. At the present time, there is a donor card process which involves the driver's licence and this has some theoretical merit but, as discussed in Dr. Robinette's subcommittee report, it has little actual impact on transplantation. The public frequently knows the wishes of their relatives with regard to certain post-mortem arrangements, and yet may remain ignorant with respect to organ donation since approximately four out of five individuals have not stated their wishes. The various options examined included the following:

(1) Presumed Consent - This is a consent form in which individuals will be presumed to have given consent to the post-mortem use of their organs unless they have stated otherwise in some written form. For example, the driver's licence would then be used to eliminate only those individuals who do not want their organs used and if one failed to sign, the medical profession would have the option to use the organs. Presumed consent has been initiated in at least seventeen countries (largely in Europe) but without evidence of increased organ retrieval. This should not be taken as proof that presumed consent is an ineffective method. The only commentary one can make is that the procurement of organs was not significantly affected and it suggests that a more important barrier to donation exists. As this conference has shown, the most significant block may be primarily professional and, until it is removed, one will not know what impact presumed consent may have. However, on philosophic grounds such a proposal is not very attractive. The relatives' act of donation at the time of a loved one's death is an act of charity

and part of the grieving process. The donation provides a situation in which a senseless death can attain some meaning and from one's despair can spring hope for others. It allows an expression of the altruism of human nature and the tremendous personal benefit that beneficence and kindness bring to the giver. There was consensus among the Task Force and the members at the Congress that presumed consent should only be used as a method of last resort.

(2) Obligatory Indication - This is a process in which, in order to obtain some government form (driver's licence, health care insurance, social insurance number), the applicant must answer a question which is phrased in this manner:

Question: Do you wish your organs used after death?
Answer: Yes ____
No ____
I don't wish to answer this question _____

Thus an individual can avoid answering the question if he or she feels it is an invasion of privacy. Polls examined at this Congress indicate that some 62% of individuals would sign "yes". We do not know what the results of the other almost 40% would be. Perhaps a good portion would not want to answer the question. However, approximately 20-30% in any population surveyed is opposed to giving consent for their own organ donation, and presumably they would record "no". This format would provide a full knowledge as to an individual's wishes and would act as a process by which an individual would be encouraged to resolve the issue. This information could be stored on a central computer and accessed by the patient or physician in order to be changed or verified. The mechanics of this proposal exist and it was determined in the course of discussions that this was a feasible plan.

However, fears were expressed that, in fact, this plan might worsen the situation rather than improve it. At the present time, less than 10% of individuals refuse when approached to donate the organs of their relatives. When surveyed, 88% of individuals would donate the organs of their loved ones whereas only 62% would donate their own organs. This suggests that fear remains prevalent with the public as to what happens after death, or individuals do not want to face their own mortality, or they want to leave such decisions to others. This difference, between those willing to donate their relatives' organs but not their own, would suggest that obligatory recording may reduce the supply of potential donors up to 30% of the present amount. This is yet to be tested in the system and research methods would have to be devised to determine the outcome of such an implementation. However, the process could provide guidance for relatives regarding the wishes of the deceased and still allow participation in the donation process since the physician would ask the relatives if they had objections to the use of the organs. The conclusion of the Task Force and Congress was that one should 'make haste slowly' in this process of establishing a better recording of individuals' wishes so that the actual number of donor organs is not diminished.

(3) Donor Card - This is a process by which an individual signs and carries a document to indicate that he/she wants the organs used after death. This method has been utilized for some 14 years in a

number of countries and has not been found to be an effective part of the donation process. It is difficult to obtain documentation of the incidence of actual donors resulting from the signing of the driver's licence or donor card. However, many donor families indicate that they wish their relatives' organs to be used because of discussions that have occurred about the signing of the driver's licence or the donor card. The donor card is endorsed by the Human Tissues Gift Act which allows the surgeon to remove the organs without further reference to relatives should a donor card be found. However, the following barriers to that procedure exist: (1) This situation has never been tested in court and physicians and surgeons would not override the expressed wishes of the next of kin if they varied from the signed card. (2) The driver's licence is infrequently near the body in the intensive care unit. With a motor vehicle accident, documents frequently go to the police station and, in post-surgery, the valuables have often been taken elsewhere. (3) Only 26% of individuals have signed their driver's licence. (4) Lastly, many people do not have a driver's licence.

Implementation

To accomplish this goal of an educated public, public awareness programs will have to be established at three levels. (1) Patients and the public will need to be educated regarding the feasibility and benefits of transplantation. Patient education materials should be distributed widely amongst patients who might benefit from transplantation and should stress benefit to the patient from the standpoint of rehabilitation, and benefit to the community as a result of economic considerations. The criteria for admission to a transplant program have to be clearly delineated. Even though transplantation is no longer considered experimental but rather therapeutic, past application has been in an experimental mode and to a rather restricted group, both by age and disease, and patients must be given current facts concerning outcome. In the same way, patients should receive education regarding the possibility of a living related donor and further research is required as to the ethics and guidelines for living unrelated donation. As the public recognizes the benefits of transplantation, they will accept the recommendations of their physicians with respect to therapy and, more particularly, will recognize that post-mortem donation of organs is an important act on their part. The concept that transplantation is experimental rather than therapeutic must be revised. As well, the use of terms such as "one year graft survival" or "one year patient survival" should be abandoned and replaced with terms which do not require an actuarial understanding but which reflect the long term nature of survival. (95% "one year survival" can be expressed as "95% of the patients survived longer than one year" or can be expressed as "5% of the patients died within the first year and the other 95% continue to survive".)

(2) A voluntary form of pre-mortem decision-making regarding donation which would promote discussion among families must be established. The best mechanisms for this are the organ donor card promotions, driver's licence promotions and a well-orchestrated public awareness program with both national and provincial activities. As well, local recruitment drives must be encouraged. This situation will never be accomplished by government edict or national advertising alone but must include lay groups which have demonstrated interest and represent a very broad cross-section of the community. There are a number of disease-related groups, such as the Canadian National Institute for the Blind, the Kidney Foundation of Canada, the Liver Foundation and others, as well as groups that are more generic and promote transplantation in general. Every effort should be made to provide materials for these groups to be used in service clubs and local drives. Donor Awareness Month and media participation in underscoring the benefit of organ donation should be coordinated through a Provincial and National Program. Studies should be performed with regard to a universal record of consent to determine if a more effective means of recording an individual's wishes can be achieved (however, care must be taken so as not to disrupt the very positive attitude of the public to donate their relatives' organs).

(3) The third area for public awareness programs concerns public and high school education. Part of the health curricula and life studies in our educational system should include the individual's responsibility to consider those life-deprived individuals who might benefit from the

donation of one's organs. Classroom discussion will generate discussion within the family with the result that organ donation will be an expected, normal form of activity rather than something unusual and tumultuous. Materials must be provided by government for the educators to help accomplish these goals.

II. Educated and Committed Profession

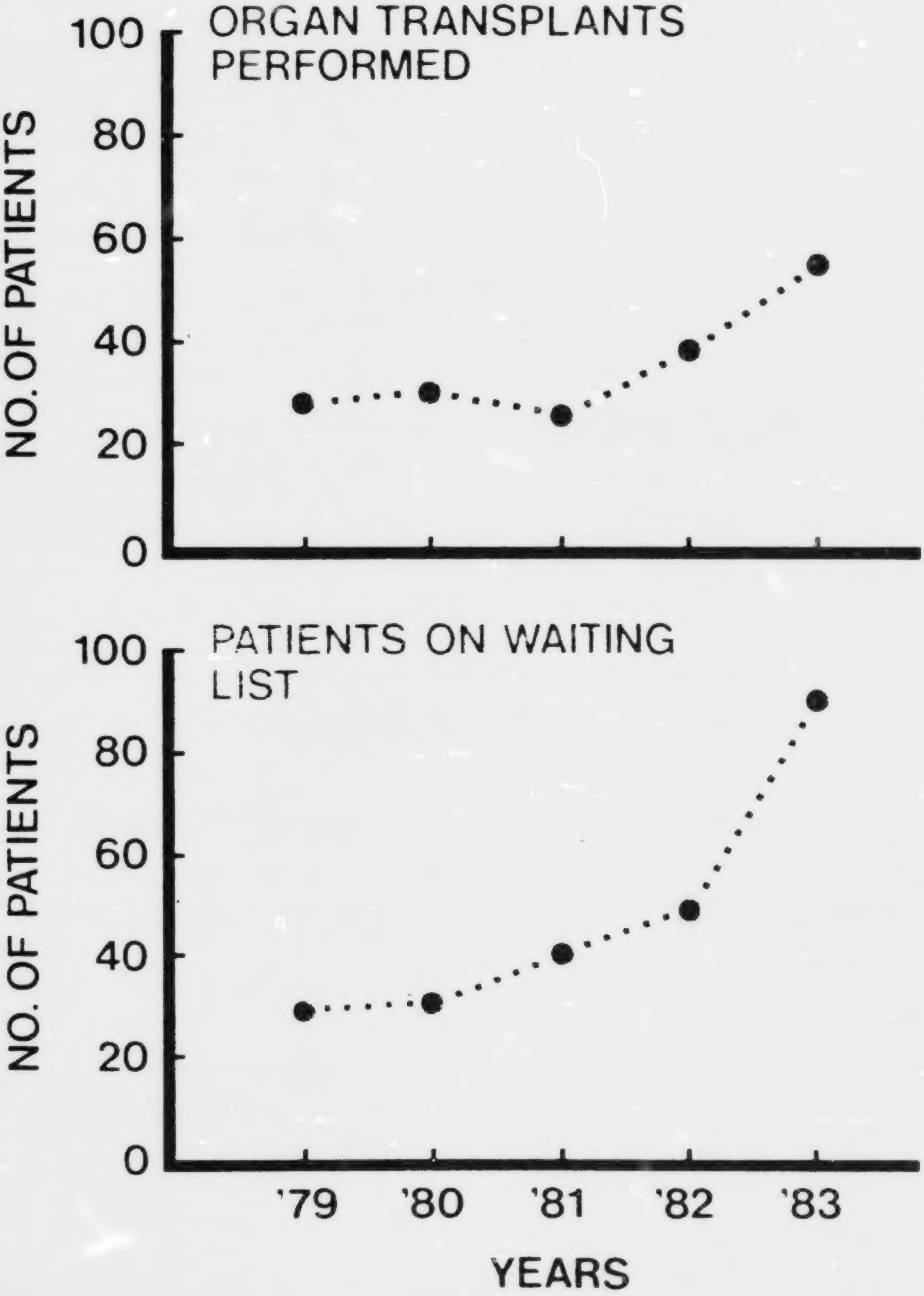
It is apparent from discussion at the Congress that the primary block in the system is the lack of request for consent, rather than the refusal of consent. The conclusion is inferential in that no study exists where this variable can be isolated. However the following facts are of interest: (1) there is a lack of antipathy amongst the public[1]; (2) there are more than 1,000 potential donors in Ontario,[2] of which only 10% are being converted to actual donors;[2] and, (3) there is an experience of less than 10% incidence of relatives refusing consent.[3] It can be concluded therefore that donors are not being identified nor relatives approached in a timely fashion. Less than 50% of potential retrievable kidneys were obtained at the largest teaching hospital in this province, in spite of a high profile transplant program with major educational efforts. The surveys have identified that a significant proportion of professionals do not know what constitutes a suitable donor[4] and this, coupled with a perceived reluctance to participate in the organ donation process,[5] leads to the major barrier in organ donation. To overcome this barrier one must educate the professions (physicians and surgeons, nurses, social workers and clergy) in order that they are committed to a professional requirement to ask for a donor organ whenever feasible. To achieve this component one needs to accomplish three goals: (1) an agreement amongst the profession as to the need for organs and tissues, (2) a recognition of a professional responsibility to participate in and accomplish the organ donation process, and (3) a recognition from insuring agencies, hospitals and government of the effort involved in obtaining donors. Parallel with this recognition, an audit of accomplishment/failure will ensure a reasonable degree of organ retrieval by establishing community standards.

To achieve agreement concerning the need for organs and tissues, the data information reported in this study (for kidneys) and in the attached projection of needs table (for other organs and tissues) emphasize the need for, and success of, transplantation. The educational process must therefore involve interaction with regional organ retrieval programs in which the benefits, in the form of successful patients, are easily discerned.

When a patient is declared brain dead, the patient's physician may frequently respond with grief and a sense of failure and guilt -- the usual response to those emotions is to terminate the process quickly but with sensitivity. Usually at that time, the coroner or pathologist assumes care of the mechanics of the disposal of the body while pastoral

TABLE 2

NUMBERS OF ORGAN TRANSPLANTS & PATIENT WAITING LIST AT UNIVERSITY HOSPITAL:



services may provide counselling. In addition, the audit function terminates at the time of death as do bed occupancy, hospital reimbursement and physician reimbursement. Therefore, an extraordinary decision on the part of the physician is required in order to involve him or herself in the process of counselling and discussing the issues surrounding brain death and organ donation. In addition, the intensity of medical monitoring of the potential donor increases. The nurse caring for a terminal patient may have begun to respond emotionally to the patient's death by accepting the inevitability of brain death. Now the nurse, as with the physician, must ignore the condition of the brain which has been declared irreparable and irretrievable and emphasize the vitality and recoverability of the retrievable organs. An intense flurry of medical activity occurs in which maintenance of cardiovascular stability is attempted. This procedure is usually performed in the middle of the night or on weekends. Until now it has been considered an act of charity for the physician or surgeon to involve him or herself in obtaining a donor. However laudable, professional charity must be replaced by professional responsibility if the organ donation process is to become a regular occurrence. A system in which the physician or team is expected to request the donation of tissues and organs upon declaration of death needs to evolve.

This system should be accurately reflected in reimbursement schedules in order that the efforts of participants be recompensed. Physicians may spend three to fifteen hours with the organ donation process. If this experience occurs only occasionally, then it does not interfere with the regular activities of a professional practice. However, only 10% of potential donors are being retrieved and it is to be expected that the frequency of occurrence will increase dramatically, particularly for medical staff involved with intensive care medicine. The surveys documented that neurosurgeons and neurologists specifically did not want a reward for their efforts and one would presume that this opinion was related to a perceived conflict of interest. Although this perception is easy to understand, there should be a process by which the professional time factor is recompensed rather than the suggestion that the specific act of identifying and obtaining a consent for donation be rewarded.

Recognition of effort is part of the assessment of a highly proficient and caring professional and organ retrieval should confer the usual rewards for a job well done and for accomplishment of such professional responsibilities. Records of the number of potential donors occurring in intensive care units and the number of conversions to actual donors, as well as the reasons why individual organs are not retrieved, should all be documented. Thus significant barriers not detected by this process, or which occur as a result of future activities, can be identified and resolved.

Implementation

The implementation of a plan to achieve these goals of an educated and committed profession will occur through the three areas of: Education, Recognition, and Audit.

(1) Education

Medical and nursing schools require adjustment of curricula in order to teach the management of the brain-dead patient, the role of post-mortem organ donation in the grieving process, and the professional requirement for retrieving all salvagable life from a body. Associated with this is the need for an updating of the curricula regarding the role of transplantation in end-stage renal failure. The educational programs of the Royal College of Physicians and Surgeons as well as scientific and professional societies should be encouraged to present educational information that allows their members to absorb the impact of this changing technology. As a result of discussion groups in the respective colleges, a consensus should be established regarding a standard of medical practice for organ donation. The continuing educational activities of the medical and nursing professional societies should emphasize the practical responsibilities that emanate from this newly recognized professional duty.

Having established a foundation of education with respect to transplantation and organ donation at the level of the professional school and professional societies, it will then be necessary to maintain a Provincial and National professional awareness program. Such programs have been useful in the introduction of new concepts to medicine. An appropriate example would be child abuse programs in which educational efforts through public means, government programs and lay groups combined to introduce and reinforce professional responsibility in a new area. The materials for this endeavour should be prepared by a central agency to ensure reliable information in a proven format that can be generally employed.

(2) Recognition and Reimbursement

The effort that is required to identify, maintain and obtain a donor is considerable and, at times, can be extreme. Presently, the schedule of fees, and indeed the classification of patients, make it such that no recompense or reward for time and effort can occur. Once declared brain dead, the patient ceases to be an occupant in the intensive care unit. Thus procedures performed on, and time involved with, the brain dead patient are not reimbursed. The government must take into account the schedule of fees presently recognized by tariff committees of the medical associations, hospital associations and the insuring agencies and establish an equitable arrangement. It has been proposed in the past by some well-meaning groups that a type of "finder's fee" be established for obtaining a donor. This concept is repugnant to most people and indicates a non-professional attitude similar to a bounty-hunter. Although this situation is to be shunned, recognition that professional duty extends beyond declaration of death must be taken into account by a fair and equitable reimbursement for time and effort involved.

Identification of a donor and obtaining of consent begins a process which may take many hours to complete. This process includes maintaining the stability of the donor from the standpoint of cardiovascular status and requires constant, intensive nursing. In a teaching hospital, intensive care staff are available, but in many hospitals in which there are no house staff and the physician is not located within the hospital, the performance of a clinical practice in addition to maintaining a potential donor is not feasible.

Therefore, it is necessary to have within each hospital a well recognized and easily identifiable support group which is responsible, if called upon, to maintain the health of the donor body until organs have been retrieved. In certain instances an individual within the hospital may be primarily responsible for this task. On the other hand, a retrieval team from the regional retrieval service may be the most feasible option and in this instance, the retrieval team can collaborate with the nursing and medical staff of the intensive care unit in which the patient resides. This collaboration requires a stated policy, identifiable resources (for which the hospital must be reimbursed by the government) and a retrieval team that is mobile. Thus, the requirement for additional expansion of the retrieval network is underscored. The concept of a Donor Retrieval Technician has been introduced in several centres, notably Pittsburgh, and found to be highly effective.

(3) Audit

If involvement with donation is to be considered a professional duty, then the professional activities that occur in relation to donation must be audited. Before this audit can occur consensus must be achieved on certain issues. Firstly, the professional/medical standards of a "recorded consideration" of donation request have to be examined in some detail. This concept entails the mandatory recording by a physician (or designate) on the hospital chart that consideration had been given to request for organ donation. Any patients who were clearly not donors, such as those individuals with cancer or widespread sepsis, would not be included but for those without definite exclusion criteria, this recording would be required in every hospital death. The record would state the outcome of the request or the reason why a request was not made. There is no jurisdiction in which this has occurred to our knowledge but "recorded consideration" represents the other end of the spectrum of current practice in which a request for organ donation is anything but routine. This concept of "Recorded Consideration" should be put forward to the medical and nursing associations and hospital associations for discussion and consensus regarding its acceptability.

Findings of the Task Force indicate that nursing teams are frequent initiators of discussions concerning organ donation, although traditionally a discussion of new therapy or alterations in therapy is a prerogative of the medical team. It would be useful for the nursing and hospital associations to discuss a nursing code of conduct to include such areas as informing relatives and alerting hospital teams of a potential donor. The nurses responsible for interpreting the condition of the patient to relatives could appropriately introduce the concept of organ donation as the patient's status changes. Nursing education could include the requisite information and skills necessary to facilitate these discussions with an eventual formal discussion with the relatives and physician leading to organ donation.

The hospital associations should be encouraged to discuss the composition of the hospital audit which is governed by the hospital Audit Committee. Patients identified as potential donors could be noted and the conversion rate from 'potential' to 'actual' donor determined and recorded. It is anticipated that hospitals of an equivalent nature, size, and staff would be reasonably similar and provide for the calculation of an expected conversion rate. Thus, particular difficulties with education or attitude might be evident. Because criteria for excluding potential donors are based upon physician judgement, it is possible for physicians to avoid the issue of organ donation by indicating that a patient is not a suitable potential donor. This type of error in judgement would be reflected in a significant deviation from the expected conversion rate and could be identified by the Audit Committee. Encouragement for audit participation may come from hospital accreditation associations and, if such a function is a required criterion for hospital accreditation, the incentive for a functional program would be significant.

III. Visible, Accessible and Verifiable Retrieval System

The research of the Task Force clearly illustrated that the majority of individuals working in the hospital system either did not know that a retrieval system was available or, if they knew, did not know how to access this system. This was even true within hospitals with a highly organized and high profile transplant program. System accessibility and a rapid response to a request that a donor be examined for potential donation is essential not only to reduce wastage of potential donors, but also to encourage participation in the organ donation process. At the present time, organ retrieval in each hospital is undertaken largely on an ad hoc basis and, although meant to be regionally organized, frequently the response within a hospital has been found to be wanting. The organization that is developed must provide for a "common number access" via a provincial or national hotline which would provide a quick response and notification of the regional group responsible for retrieval of organs within the area of request. As well, an individual or group of individuals within the hospital who could facilitate the management of the donor and obtaining of consent, with a good working relationship with the regional retrieval group, would be notified. Defined guidelines and hospital policy with a concurrent audit would govern and direct the activities within each hospital. The ideal system would have therefore the following components:

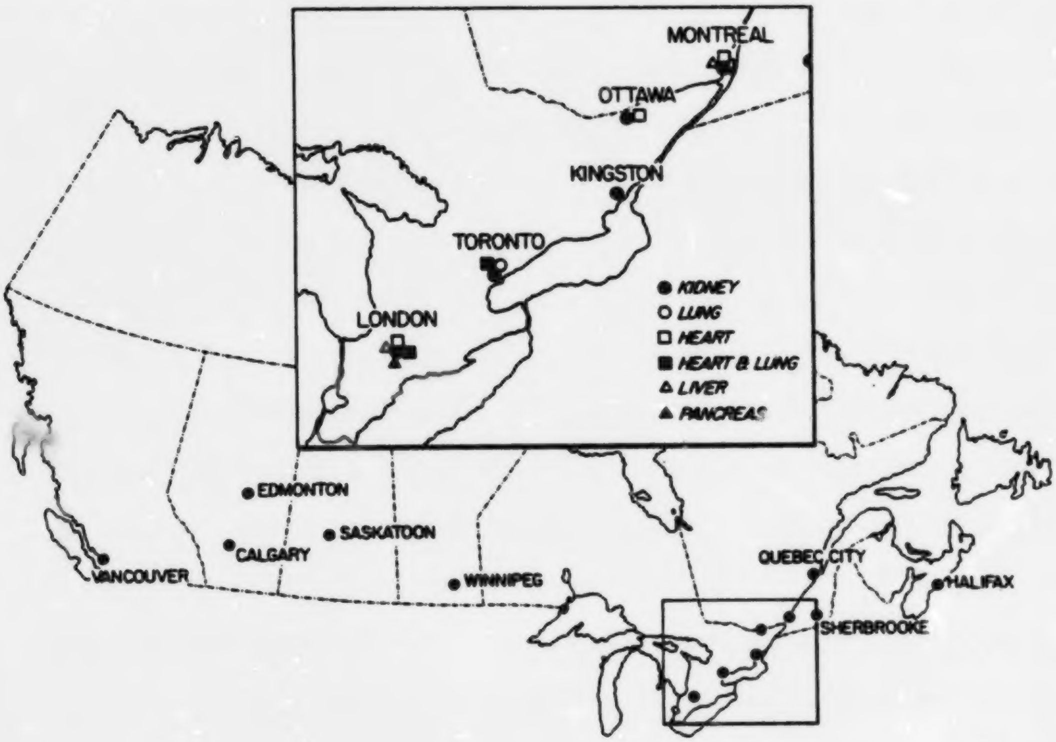
(1) Provincial (National) Hotline

This should be a common number which is available in all emergency and intensive care units and hospital switchboards. Extramural agencies such as police and ambulance would also have this number available. The hotline should be a twenty-four hour answered service in which an individual physician or nurse would call and indicate that they had a patient who was a potential donor and the location. This information would be taken and the regional retrieval program notified. The response time for the central answering service to contact the transplant coordinator or physician at the regional retrieval centre, and for that individual to be in direct communication with the physician or nurse who made the original request, should be no greater than fifteen minutes.

(2) Regional Retrieval Groups

The regional retrieval groups that exist in the province (Figure 2; + Hamilton) are to be responsible for the efficient retrieval of all donors referred. This entails the twenty-four hour availability of a transplant coordinator and a physician or surgeon who can discuss the care of the donor. The retrieval team, particularly with respect to multiple organ retrieval, will need to be mobile in order to go into the periphery and remove all organs that are donated. The maintenance of the donor until the time of retrieval may require the introduction of a donor retrieval technician who goes to the intensive care unit where the donor is being cared for and assists with the cardiovascular stabilization and general clinical optimization for organ retrieval. This individual could also be responsible for assisting the local hospital with identifying itinerant surgeons and undertaking some of the organizational overlap required for a smooth operation. When only kidneys are involved, the interaction is usually by phone and between the physician or surgeon in the retrieval program and the surgeon involved at the donor hospital. This is a physician-to-physician process, and it is essential that it be performed on a regional basis. Coordination over long distances and amongst people who are strangers to each other does not facilitate organ retrieval.

FIGURE 2


MONTREAL
OTTAWA
KINGSTON
TORONTO
LONDON
● KIDNEY
○ LUNG
□ HEART
■ HEART & LUNG
△ LIVER
▲ PANCREAS
EDMONTON
CALGARY
SASKATOON
VANCOUVER
WINNIPEG
QUEBEC CITY
HALIFAX
SHERBROOKE

One of the troublesome problems discussed at the Congress was the determination of credentials of itinerant surgeons, physicians and transplant coordinators. These members of the group should be known to each other and a package of identity papers needs to be developed so that when they arrive and require operating room privileges, the medical director or chief of surgery of that hospital can identify not only the individual but the adequacy of his credentials to perform in the hospital. At the same time, a method of identifying precisely the destination of the donor organs to avoid mixup is necessary for both legal and medical purposes as an increasing number of transplantable organs are interchanged.

(3) Hospital Donor Facilitator

There was consensus that each hospital needs an individual appointed by the Medical Advisory Committee (M.A.C.) to be responsible for facilitating organ donation. This individual would head a committee or direct a group of individuals operating under a well defined hospital policy, and would be a resource person for individuals in the hospital who wish to discuss organ donation or specifically arrange for a patient to be an organ donor. This individual would have close, established contact with the regional retrieval centre and would be completely apprised of medical and legal matters surrounding this issue of organ donation. As well, this individual could be responsible for that portion of the medical audit related to the determination of donor identification and conversion rates.

(4) Guidelines and Hospital Audit

Defined Guidelines: Each hospital would have a policy regarding organ donation. It would state the hospital policy to promote post-mortem donation of organs and facilitate any relatives wishing to do so. The question is whether or not there would be a policy of recorded consideration of donation request. The sensitivity of each hospital board and its physicians differs on this and should be respected. The policy would address the problems of emotional conflict such as that faced by a nurse when the patient she is looking after and attempting to help recover life becomes a donor, and the maintenance of the body is no longer for that individual's own long-term survival. In some situations, a change in nursing staff for that patient may be important for the emotional well-being of the nursing staff, and should be a consideration in the formation of the hospital policy. The criteria for the diagnosis of brain death and its documentation are required in hospital policy. The time of death should be the time of brain death, and so there will be a time after the patient's death that nursing procedures continue, laboratory work is performed and bed occupancy occurs. The determination of whether organ removal is an elective or emergency procedure is an important policy item and has been a reason for the loss of many organs. A statement regarding itinerant surgeons and, on the other side, the removal or transport of the donor body must be covered in that policy. As well, information provided to relatives regarding the destination of the organs and interaction with the media need to be detailed in the hospital policy.

Audit: An audit of organ donation activities of the hospital requires a definition of a potential donor and then a tracking of that patient to determine the post-mortem destination of the organs. A form should appear on the hospital chart in which the patient is identified and the request for donation of organs identified as "made" or "not made", followed by the destination of the individual organs. This audit has important potential legal connotations, but the only way that a hospital will be able to determine its conversion rate from potential donor to actual donor will be on this basis. Such an audit should be a component of the statistics of a hospital, similar to the percentage post-mortem rate, which is a part of the regular audit reporting within hospitals in this country. The guidelines for the identification of potential donors can be agreed upon by the hospital association and thereby standardized.

Implementation

(1) Provincial Multiple Organ and Retrieval Exchange Program (MORE)

The MORE program must be recognized as a truly provincial umbrella organization and become highly visible. The hotline number should be ubiquitous, posted in all emergency departments, intensive care units, hospital switchboards, ambulances and police stations. A twenty-four hour answering service with informed operators is required and would be the key to providing a fifteen minutes response time to any request. The primary functions of this program are to provide easy access, rapid notification of the regional retrieval programs, and efficient exchange of the organs following retrieval. The public awareness programs and materials for professional awareness programs should emanate from this group.

(2) Regional Organ Retrieval Programs

Regional Retrieval Programs will require additional funding for staffing requirements, cross-match facilities, and transportation. The funding for these components need to be recognized as regional funding. The costs of the retrieval team and transportation can be identified and budgets established for renal and extra-renal transplants.

(3) Donor Hospital Programs

Hospital policy guidelines will need to be devised and standardized with the collaboration of the Hospital Association and the Medical and Nursing Associations. Specifically, hospital policies will need to be devised with regard to recorded consideration of requests, declaration of brain death, donor identification, donor management, and credential verification for hospital privileges of itinerant physicians and surgeons. The concept of "recorded consideration" has not been worked out and will require some considerable discussion but, as an interim step, the guidelines for determining the wishes of the deceased or the next of kin should be identified and the hospital indicate to the nurses and physicians that it is considered a good practice to determine the preference of the relatives when they are informed of brain death. The criteria for declaration of brain death as enunciated in the CMA recommendations should be adopted as interim policy, and the CMA should be encouraged to re-examine those criteria and add the statements on brain flow studies. Donor identification criteria should be stated in general terms so that changing criteria can be applied but in general a "wide net" should be cast in order not to overlook donors and the determination that a donor is not suitable can be made by the regional retrieval consultant. The hospital donor facilitator could be responsible for continuous updating of the criteria for donor suitability. Guidelines for donor management include ethics concerning the separation of transplant and therapeutic teams, but should also include recommendations for donor management and donor transportation.

The development of portable credentials for granting of hospital privileges should be arranged in collaboration with the College of Physicians and Surgeons and the Hospital Association and must include photographic identification of the individual. A registry could be established ahead of time through interchange between the transplant centres, but changing personnel would necessitate some type of portable credential.

(4) Hospital Donor Facilitator

A new position with the health care team at a hospital would be the Hospital Donor Facilitator. This individual would be recruited from amongst the general medical staff and would assume the responsibility of continuing education, donor awareness, and serve as a consultant for the management of potential donors in a hospital. This individual would also maintain communication with the Regional Retrieval Centre and with the provincial and national programs for educational update. The definition of this individual's position and his/her lines of responsibility to the head of a department, the Medical Director or the Medical Advisory Committee should be worked out with the College of Physicians and Surgeons and the Hospital Association. Remuneration could be a fee for service or could be recognized as a hospital program and, as such, an administrative or retainer fee could be identified.

(5) Hospital Reimbursement

The costs for donor care have been studied in several hospitals but accurate accounting should be established and a method negotiated with the government to reimburse hospitals for donor care. These costs include the Hospital Donor Facilitator as well as the Intensive Care Unit costs that invariably accompany these patients. From time to time, attempts to obtain donors are abortive and financial recognition of this situation is essential so as not to inhibit attempts to obtain questionable donors.

(6) Audit

Guidelines for medical record classification of potential donors should be established in consultation with the Hospital Accreditation Association and the Hospital Association. A method for identifying potential donors on admission or during hospital stay and then determining the destination of organs should be developed. This would allow for the determination of conversion rates of potential to actual donors and provide an indication of organ or tissue wastage.

A provincial audit or registry needs to be established which would allow the accurate recording of inter-institutional exchange of organs. Not only is this essential in reflecting efficiency, but it is of importance in avoiding organs or tissues leaving the system and finding their way into a black market.

IV. Efficient and Equitable Organ Distribution

(1) Efficient Organ Storage and Distribution

Organ viability following retrieval is directly related to the duration of storage. An efficient and rapid organ distribution system is thus of fundamental importance to provide a graft for an appropriate recipient with the shortest delay. To facilitate this exchange, tissue typing must be performed rapidly in the retrieval centre, identification of the appropriate recipient made quickly through a centralized computer file, and the organ dispatched to the transplanting centre by the most direct and efficient route. Within the transplanting centre, comparable alacrity is essential. Recipient readiness must be verified quickly by the patient coordinator and transplant team, recipient transport ensured to minimize time delays, and the transplant procedure itself must be considered an urgent undertaking and no longer relegated to its traditional place after hours as an elective procedure.

Further exploration of the optimum method of organ storage during this period of time must be undertaken and accorded high priority. Implicit in these studies are considerations both of effectiveness and cost, and facility of transportation within the province.

Efficient use of this limited resource of donor organs entails distribution of the organ to an appropriate recipient to maximize the possibility of graft success. Parameters such as tissue matching and recipient sensitization utilized to define appropriate donor/recipient combinations must be clearly defined by the medical personnel within the transplanting institutions, and organ distribution performed within the provincial program according to these parameters.

(2) Equitable Distribution of Organs

Exchange of organs is essential to achieve optimal organ usage and graft survival. Regulation of distribution is essential to avoid marked operational inequities such that certain regions become net organ producers while others are net consumers for organs retrieved. Consensus regarding an equitable distribution formula between the transplanting centres within the provincial distribution network is thus essential to maintain the incentive for donor identification and to increase the global number of organs available for transplantation within the province.

References

1. Donation Process Subcommittee Report: 101-102
2. Summary of Task Force Findings: 14
3. University Hospital: Personal Experience
4. Donor Identification Subcommittee Report: 87
   Donation Process Subcommittee Report: 108
5. Donation Process Subcommittee Report: 113
   Summary of Task Force Findings: 20

SECTION III:

ORGAN DONATION IN THE EIGHTIES

A BLUEPRINT FOR SUCCESS

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TABLE OF CONTENTS

1.0 INTRODUCTION.. 71

2.0 OBJECTIVES 71

3.0 INFORMATION BASE 72

4.0 RESULTS
- 4.1 Chief Executive Officer Survey 73
- 4.2 General Survey Questionnaire
  - 4.2.1 Initiator of Organ Donation Process 75
  - 4.2.2 Assessment of the Availability of Assistance 77
  - 4.2.3 Suitability of Potential Donors............. 80
  - 4.2.4 Clinical Experience with Potential Kidney Donors 82
  - 4.2.5 Problems Encountered with Potential Kidney Donors 82
  - 4.2.6 Results of the Donation Experience 83
  - 4.2.7 Helpful Stimuli for Organ Donation 84

5.0 DISCUSSION AND CONCLUSIONS
- 5.1 Chief Executive Officer Survey 86
- 5.2 Initiation of Organ Donation Process and Assessment of Available Assistance 87
- 5.3 Suitability of Potential Donors 87
- 5.4 Clinical Experience with Potential Kidney Donors 87
- 5.5 Discussion Session 88

1.0 INTRODUCTION

There are some hospitals or physicians which consider possible donors with certain categories of illness as unacceptable. However, the potential donor may be completely acceptable for another program which would willingly utilize the kidneys. Hospital practices, in particular the policies relating to the intensive care unit which are largely defined by historical biases, determine what is an "acceptable donor". The definition of an "acceptable organ donor" differs from community to community but more particularly has changed with the passing of time. With these changes the education of professionals involved and the public have not kept pace.

The mandate of the Donor Identification Subcommittee was to identify the factors which trigger or prevent organ donation in the hospital milieu. The committee members agreed that there was inadeqate information presently available to address this problem. They further agreed that there are misconceptions and fallacies concerning the value of organ donor cards.[1] Even though recent reviews address many aspects of the donation process, there was insufficient data to reach conclusions about the factors either promoting or hindering donor identification.[2,3] It was therefore decided that a survey of health professionals in the Intensive Care Units (I.C.U.)of Ontario hospitals was the most appropriate method for obtaining comprehensive and reliable data.

2.0 OBJECTIVES

The objectives defined by this subcommittee were:

(a) To determine the manner by which potential kidney donors are presently identified in hospitals throughout Ontario.

(b) To identify and define features that contribute to suitability of a patient as a kidney donor.

(c) To study the factors (particularly the inhibiting ones) affecting identification of individuals as a potential organ donor.

(d) To recommend ways of overcoming these barriers to donor identification in order to improve the supply of donated organs.

3.0 INFORMATION BASE

The information required by the subcommittee was obtained from three sources: personnel in the intensive care units in Ontario hospitals; Neurosurgeons and Neurologists in Ontario; and hospital administrators. One hundred and eighteen (118) hospitals in Ontario which have intensive care units received a general survey questionnaire as part of a Donor Identification and Professional Barrier Survey conducted by Burton and Associates*. Individually, both medical and allied health professionals who worked in these units during a one-month period between July and September 1984 were asked a series of questions related to the donor identification process. Additionally the questionnaire was sent to sixty (60) neurosurgeons and one hundred and twenty-one (121) neurologists in Ontario.

The questionnaire reflected the specific concerns of the subcommittee including:

1. Who generally initiates the donation process in the hospital environment?
2. Are these professionals aware of existing organ transplant retrieval programs?
3. Are there hospital-based systems which help the professional individual to initiate the donation process?
4. Does the health care professional have adequate knowledge of what constitutes a suitable donor?
5. Has there been any adverse effect on organ donation as a result of a previous experience with organ donation?
6. Are the personal attitudes and opinions towards organ donation a negative factor in organ retrieval?
7. In the opinion of the health professionals what are the specific barriers to organ donation?
8. What methods are acceptable to health professionals to promote awareness of organ donation?

*NOTE: Further research has been conducted and final data are available. Address any enquiries to: Dr. H.J. Burton, Department of Psychiatry, Toronto Western Hospital, 399 Bathurst Street, Toronto, Ontario.

A Chief Executive Officer Questionnaire was sent to all hospital administrators to elicit their responses as to possible barriers or impediments of organ donor identification.

4.0 RESULTS

4.1 Chief Executive Officer

Results of the Chief Executive Questionnaire are summarized in Table 1 in which the response frequencies are provided. When these results were further analyzed as to whether the hospital had a renal program (either a dialysis or transplant program) vs. those hospitals that did not have a program (non-renal hospital), the following results were obtained.

TABLE 1: RESULTS OF EXECUTIVE OFFICER QUESTIONNAIRE

QUESTION		RESPONSE FREQUENCY (PERCENTAGE) "YES"	"NO"	TOTAL
1.	Does a specific organ donation policy exist at your hospital?	42(44.7)	52(55.3)	94
2.	Does your hospital actively promote organ donation?	43(45.7)	51(54.3)	94
3.	Is there an individual or team that is responsible for co-ordinating the donation process?	26(27.4)	69(72.6)	95
4.	Reasons for stating "NO" to any of the preceding questions:			
	a) No interest expressed by medical staff	23(47.9)	25(52.1)	[illegible]
	b) No interest expressed by hospital board	18(39.1)	28(60.9)	46
	c) Service population is restricted such that donors are a rare occurrence and therefore not an issue	38(67.9)	18(32.1)	56
	d) The organ donation process is handled by other hospitals in your area	32(64.0)	18(36.0)	50
	e) Unaware of how the donor process works	21(40.3)	31(59.6)	52
	f) Had negative experiences in past regarding organ donors	4(8.5)	43(91.5)	47
5.	Do you feel your hospital would refer donors:			
	a) given changes in hospital policy	36(63.2)	21(36.8)	57
	b) if actively sought by an outside centralized agency	68(85.0)	12(15.0)	80
	c) if financial reimbursement was made available.	38(62.3)	23(37.7)	61

(1) A specific organ donation policy did not exist in approximately 55% of all hospitals surveyed. 93% of hospitals with a renal program stated they did have an organ donation policy whereas only 36% of the non-renal hospitals had a specific organ donation policy (p=.003).

(2) 54% of hospitals stated that they did not actively promote organ donation. In hospitals with renal programs approximately 7% stated that they did not promote organ donation whereas 63% of the non-renal hospitals did not promote organ donation (p. .002).

(3) 72% of the Chief Executives stated that there was no individual or team that was responsible for co-ordinating the donation process in their hospital. In the renal hospitals 15% of respondents stated that there was no team whereas in non-renal hospitals 83% said that there was no such team (p = .0001).

Reference to Table 1 #4 indicates that lack of interest by either the medical staff or the hospital Board appears to be a significant factor concerning the donation process. A previous negative experience regarding organ donation was felt to be contributory with nine percent (9%) of the respondents.

The Chief Executives felt that change in hospital policy, active participation by an outside centralized agency and financial reimbursement were all factors which would enhance organ donation in their hospital.

4.2 General Survey Questionnaire

4.2.1 Initiator of Organ Donation Process

The overall results to this question of initiation are provided in Table 2. The frequency of positive responses to the question "Who initiates the donation process?" are summarized in Table 3. The number of positive responses (sometimes, usually, and always) have been summed and positive responses were then classified according to the health professional and the type of hospital from which the response originated.

TABLE 2: RANKING OF PERSONS INITIATING CONSIDERATION OF POTENTIAL DONOR

	RESPONSE FREQUENCY (PERCENTAGE)					
PERSON INITIATING	1 NEVER	2 SELDOM	3 SOMETIMES	4 USUALLY	5 ALWAYS	6 DON'T KNOW
1. PATIENT	603 (34.1)	588 (33.3)	290 (16.4)	36 (2.0)	10 (.6)	239 (13.5)
2. RELATIVE	600 (34.1)	602 (34.2)	343 (19.5)	32 (1.8)	4 (.2)	181 (10.3)
3. CHAPLAIN	1,181 (70.1)	146 (8.7)	74 (4.4)	9 (.5)	1 (.1)	293 (16.2)
4. NURSE	592 (22.7)	401 (25.7)	454 (25.7)	133 (7.5)	17 (1.0)	167 (9.5)
5. INTERN	496 (43.9)	178 (15.7)	230 (20.3)	65 (5.7)	10 (.9)	152 (13.4)
6. RESIDENT	405 (35.7)	101 (8.9)	252 (22.2)	230 (20.3)	27 (2.4)	118 (10.4)
7. ATTENDING PHYSICIAN	385 (21.1)	417 (22.9)	470 (25.8)	327 (18.0)	43 (2.4)	179 (9.8)
8. OTHER PHYSICIAN	178 (28.1)	79 (12.5)	177 (27.9)	67 (10.6)	21 (3.3)	112 (17.7)
9. OTHER	90 (48.1)	11 (5.9)	15 (8.0)	3 (1.6)	2 (1.1)	66 (35.3)

TABLE 3: INITIATION OF ORGAN DONATION

	Frequency of Positive Responses			
Person/Factor Initiating Donation	Transplant Hospital	Dialysis Hospital	Other	All Hospitals
Physician	69%	53%	30%	41%
Nurse	50%	51%	28%	35%
Organ Donor Card	23%	22%	18%	19%
*Other	18%	20%	12%	12%
TOTAL	40%	36.5%	22%	26.8%

* Includes Relatives, Chaplains and Others

The overall frequency of positive responses was only 27%. Thus, 73% of the responses were negative (either never, seldom or don't know). The frequency of positive responses was 40% and 37% respectively in hospitals with either a transplant or dialysis program as compared to 22% in hospitals without such programs.

The physician is the most likely individual to initiate organ donation overall and in each of the three hospital categories. However, nurses do initiate the process 35% of the time overall and this is higher in hospitals with a renal program. The organ donor card and other individuals are less likely to initiate organ donation.

The following conclusions can be drawn from the responses to this question.

a) The physician, either the attending physician, resident or intern or ICU physician, is most likely to be the person who initiates the donation process. It is more likely that residents and interns will initiate the process in hospitals which have these positions whereas in other hospitals the attending staff physician is more likely to initiate the process. Other health care professionals do play a role in initiating the donation process. Nurses rank slightly behind physicians as the most likely professional to initiate the donation process.

b) A signed organ donor card is less likely to initiate organ donation as compared to either a nurse or physician.

4.2.2 Assessment of the Availability of Assistance

Two aspects to assess the availability of assistance once the donation process has been initiated were measured. The first aspect concerned the availability of telephone advice (Tables 4, 5) and 55% of the respondents said that there was a telephone number available for advice or assistance. In those hospitals with a renal program over 65% of the respondents were aware of a telephone number as compared to 53% of those from other hospitals. When the question was asked as to which individuals would most likely be contacted, the nursing supervisor was most frequently mentioned, physicians were second with the hospital transplant co-ordinator being the third. The frequency of calling the nursing supervisor did not vary whether the individual was in a renal or non-renal hospital.

TABLE 4: AVAILABLE TELEPHONE NUMBER

RESPONSE		FREQUENCY (PERCENTAGE)
YES		1120 (56.6)
NO		108 (5.5)
DON'T KNOW		751 (37.9)
	TOTAL	1979 (100.0)

TABLE 5: WHO WOULD BE TELEPHONED

	A. INDIVIDUAL INDICATED	NUMBER OF RESPONSES	PERCENTAGE OF "YES"
1.	HOSPITAL TRANSPLANT CO-ORDINATOR	251	22.4
2.	ADMINISTRATOR	35	3.1
3.	NURSING SUPERVISOR	513	45.8
4.	PHYSICIAN	447	39.9
5.	OTHER INDIVIDUAL	68	6.1

	B. SERVICE INDICATED	NUMBER OF RESPONSES	PERCENTAGE OF "YES"
6.	M.O.R.E.	538	48.0
7.	NEPHROLOGY	279	24.9
8.	TRANSPLANT CENTRE	209	18.7
9.	SOCIAL SERVICES	45	4.0
10.	PASTORAL SERVICE	97	8.7
11.	OTHER SERVICE	30	2.7

If a service was to be contacted the Multiple Organ Retrieval and Exchange Program (M.O.R.E.) was the most common choice with 48% of the respondents indicating that they would call M.O.R.E., 26% would call a Nephrology Service and about 19% would call another transplant centre.

The second aspect of assistance addressed the problem of management of a potential kidney donor and which personnel in the hospital milieu would be contacted (Table 6). The majority of respondents would contact either a nephrologist or a urologist in the management of the donor but a significantly high percentage would also have called the organ transplant team, social worker or a chaplain if one was available. The organ transplant team was more likely to be called if the respondent worked in a hospital with a transplant program (80% frequency) vs. a dialysis hospital (48%) and a non-renal hospital (31%). There were 277 respondents who said that there was no one available to help with the management of a potential donor. One of these responses came from a person working in a transplant hospital and 264 came from professionals working in other hospitals.

TABLE 6 WHO WOULD HELP IN MANAGEMENT OF POTENTIAL DONOR

	WHO WOULD HELP	RESPONSE FREQUENCY (PERCENTAGE) "YES"		"NO"		TOTAL
1.	NEPHROLOGIST/ NEPHROLOGY TEAM	749	(68.3)	348	(31.7)	1097
2.	UROLOGIST	844	(75.4)	276	(24.6)	1120
3.	ORGAN TRANSPLANT CO-ORDINATOR TEAM	380	(44.4)	476	(55.6)	856
4.	SOCIAL WORKER	430	(50.2)	427	(49.8)	857
5.	CHAPLAIN	485	(53.9)	414	(46.1)	899
6.	NO ONE	277				277

4.2.3 Suitability of Potential Donors

This aspect of the committee's research assessed the knowledge of the responsents as to the suitability of potential donors. Each section has been analyzed as to the percentage of respondents that correctly answered the question (Table 7)

(a) A young otherwise healthy brain dead individual is a definite potential donor.
95% of the respondents answered this question correctly.

(b) Primary malignancy outside of the central nervous system is definitely a contraindication to a patient becoming a potential donor.
58% of the respondents answered this question correctly.

(c) A patient with disseminated malignancy is a definite contraindication to a patient becoming a potential donor.
93% of the respondents answered this correcty.

(d) A patient with a primary brain tumor is possibly or definitely a suitable donor.
Approximately 75% of the respondents answered this correctly.

(e) A patient with systemic infection is definitely not a donor.
87% answered this correctly.

(f) A patient with high blood pressure may possibly be a donor.
51% answered this correctly.

(g) A patient with diabetes may possibly be a donor.
36% answered this correctly.

(h) Patients with hepatitis and AIDS are definitely not donors.

(i) Patients over 50 years of age are possibly donors.
75% answered this correctly.

(j) Patients with fever are also potential donors.
67% answered this correctly.

(k) Hyptensive patients may be possible donors.
72% answered this correctly.

TABLE 7: PATIENTS INDICATED AS POTENTIAL DONORS

		RESPONSE FREQUENCY (PERCENTAGE)					
		1		2		3	
	QUESTION	DEFINITELY		POSSIBLY		DEFINITELY NOT	
1.	YOUNG, OTHERWISE HEALTHY	1897	(95.3)*	89	(4.5)	5	(.3)
2.	PRIMARY MALIGNANCY, EXCEPT IN CNS	80	(4.3)	693	(37.6)	1068	(58.0)*
3.	WITH DISSEMINATED MALIGNANCY	10	(.5)	119	(6.5)	1715	(93.0)*
4.	WITH BRAIN TUMOUR	341	(18.3)	1046	(56.0)*	481	(25.7)
5.	WITH SYSTEMIC INFECTION	14	(.7)	218	(11.7)	1633	(87.6)*
6.	WITH HIGH BLOOD PRESSURE	32	(1.6)	949	(51.5)*	880	(47.3)
7.	WITH DIABETES	32	(1.7)	661	(35.7)*	1158	(62.5)
8.	WITH HEPATITIS	13	(.7)	127	(6.8)	1729	(92.5)*
9.	WITH AIDS	16	(.9)	46	(2.5)	350	(18.7)*
10.	OVER 50 YEARS OF AGE	120	(6.4)	1402	(74.9)*	350	(18.7)
11.	WITH FEVER	66	(3.6)	1237	(66.8)*	549	(29.6)
12.	HYPOTENSIVE	119	(6.4)	1338	(71.8)*	407	(21.8)

*Correct Response

4.2.4 Clinical Experience With Potential Kidney Donors

Approximately 50% of the respondents had previous experience with a potential kidney donor although this experience varied considerably in the different hospitals. 80% of those respondents in a transplant hospital had experience with kidney donation as compared to 61% in dialysis hospitals and 42% in the other hospitals. All 32 neurosurgeons who were located in non-renal hospitals did have experience with kidney donation. There were more nurses in transplant hospitals who had experience with kidney donation as compared to nurses in dialysis hospitals and non-renal hospitals. In the transplant and dialysis hospitals over 80% of residents and ICU physicians had experience with kidney donation.

TABLE 8: CLINICAL EXPERIENCE WITH POTENTIAL KIDNEY DONOR

RESPONSE		FREQUENCY (PERCENTAGE)
YES		989 (49.4)
NO		1011 (50.5)
	TOTAL	2000 (100.0)

4.2.5 Problems Encountered With Potential Kidney Donors

This question was designed to determine the barriers to donation that the respondents encountered once an individual had been considered a potential kidney donor. The majority of the respondents claimed that the most common problem was refusal by the family to give consent for donation (Table 9). 64% of those who responded said that this was the most common problem. In the transplant hospitals over 75% of all the respondents agreed that this factor was the most frequent problem. 70% of those in renal hospitals and 56% of those in other hospitals also felt that this was the major problem with potential kidney donation. 38% of the respondents said that the unavailability of the family was the problem and approximately 19% said lack of support from medical personnel was a problem.

TABLE 9: PROBLEMS ENCOUNTERED WITH POTENTIAL KIDNEY DONORS

PROBLEM	RESPONSE FREQUENCY (PERCENTAGE) "YES"		"NO"		TOTAL
1. FAMILY REFUSED CONSENT	653	(64.3)	363	(35.7)	1016
2. FAMILY UNAVAILABLE/ UNKNOWN	368	(38.2)	595	(61.8)	963
3. NO ONE TO CALL FOR ADVICE	113	(11.9)	838	(88.1)	751
4. LACK OF SUPPORT FROM HOSPITAL ADMINISTRATION	68	(7.2)	881	(92.8)	949
5. LACK OF SUPPORT FROM MEDICAL PERSONNEL	182	(18.9)	780	(81.1)	962
6. PROBLEM WITH CORONER	41	(4.4)	893	(95.6)	934
7. OTHER PROBLEMS	58				57

4.2.6. Results of the Donation Experience

Two questions were designed to determine whether the donation experience had an adverse effect on the respondents (Table 10, 11). 44% felt that they were encouraged by the effect of the donation experience. 9% were discouraged and 47% of the respondents stated there was no effect. Of those with prior experience, 56% said that they received information on the outcome and 44% said they did not.

TABLE 10: RECEIVED INFORMATION ON OUTCOME

RESPONSE	FREQUENCY (PERCENTAGE)
YES	536 (55.7)
NO	427 (44.3)
TOTAL	963 (100.0)

TABLE 11: EFFECT ON DONATION EXPERIENCE

RESPONSE	FREQUENCY (PERCENTAGE)
ENCOURAGED	447 (43.7)
DISCOURAGED	95 (9.3)
NO EFFECT	481 (47.0)
TOTAL	1023 (100)

4.2.7 Helpful Stimuli for Organ Donation

This question was designed to determine what would be most acceptable to the respondents in terms of reminders for organ donation (Table 12). The most frequent responses as to helpful stimuli were as follows:

(1) Information in the form of literature.
(2) Media Information.
(3) Lectures and seminars to both professionals and the public.
(4) Continuing in-service education.
(5) Regional organ retrieval and exchange service.
(6) 44% thought regular telephone calls to the ICU regarding potential donors was helpful.
(7) 40% thought specific remuneration to the professional staff for donor involvement would be a helpful stimulus.

TABLE 12: HELPFUL STIMULI FOR ORGAN DONATION

STIMULI	RESPONSE FREQUENCY (PERCENTAGE) "YES"		"NO"		TOTAL
1. INFORMATION IN THE FORM OF LITERATURE TO BE PROVIDED	1827	(93.9)	118	(6.1)	1945
2. MEDIA INFORMATION	1624	(86.6)	251	(13.4)	1875
3. REGULAR TELEPHONE CALLS TO ICU REGARDING POTENTIAL DONORS	803	(44.6)	999	(55.4)	1802
4. LECTURES AND SEMINARS TO BOTH PROFESSIONALS AND PUBLIC	1821	(93.8)	120	(6.2)	1941
5. CONTINUING IN-SERVICE TRAINING	1602	(86.6)	248	(13.4)	1850
6. REMUNERATION TO PROFESSIONAL STAFF FOR DONOR INVOLVEMENT	711	(39.4)	1077	(60.6)	1778
7. REGIONAL ORGAN RETRIEVAL AND EXCHANGE SERVICE	1618	(90.9)	161	(9.1)	1779
8. OTHER	115				115

5.0 DISCUSSION AND CONCLUSIONS

The failure to obtain an adequate number of donors for organ transplantation is related to many factors.[2,4,5] Organ donor cards are probably not an effective means of increasing the supply of donors because of the small number of people who carry the cards at the time of death and the fact that physicians may still require family consent even with a signed organ donor card.[6] The hospital based barriers have been partially defined [2,3] but no study has specific data concerning these barriers. This study was undertaken to obtain such data and the following conclusions have been reached.

5.1 CHIEF EXECUTIVE OFFICER SURVEY:

There are several hospitals in the Province which have Intensive Care Units and presumably have potential organ donors but do not have a specific organ donation policy. A significant number of hospitals in the province do not actively promote organ donation. Most do not have a specific individual or team that is responsible for co-ordinating donation in their hospitals and, therefore, the person or factor triggering donation is unclear and varies considerably from hospital to hospital. This problem was most prevalent in the hospitals without a renal program.

Therefore, it is suggested that each provincial hospital with an I.C.U. should design an organ donation policy identifying a specific team or individual to be responsible for facilitating the donation process and providing specific guidelines. Additionally, each hospital should establish an Organ Donor Committee to meet regularly to review donor policy, number of potential and actual donors in-hospital, on-going education and program costs.

5.2 INITIATION OF ORGAN DONATION PROCESS AND ASSESSMENT OF AVAILABLE ASSISTANCE:

Physicians and nurses are the most likely health professionals to initiate organ donation. The organ donor card is responsible for initiating the donation process in a small percentage of instances. Although there is a provincial telephone number available, a significant percentage of health professionals (45%) were not aware of a telephone number to call for assistance. Approximately half of the respondents indicated that they would call the Multiple Organ Retrieval and Exchange Program (M.O.R.E.) if a service was to be contacted. Other respondents would contact the nursing supervisor if an individual was to be contacted for assistance with donation.

However, it is concluded that the availability of assistance in the donation process is not optimal. It is suggested that:

(1) each hospital be part of a regional organ donor system and interact with that system via regular meetings with exchange of information regarding organ donation and results of transplantation and

(2) the regional organ donor organization (or unit) interact with a provincial organ donor organization such as M.O.R.E. This could be accomplished by increasing the size, scope and influence of M.O.R.E. so that it could interact with all regional units and co-ordinate transplantation in the province.

5.3 SUITABILITY OF POTENTIAL DONORS:

The majority of the respondents answered questions concerning suitability of potential donors correctly, however, in each category there were large percentages of individuals who answered questions incorrectly. It appears that the definition of a suitable donor is not well-known to health care professionals and, therefore, educational measures to increase knowledge of possible donor characteristics would be beneficial.

5.4 CLINICAL EXPERIENCE WITH POTENTIAL KIDNEY DONORS:

The health professionals felt that the most common barrier to transplantation was refusal by the family to give consent for donation. Other significant barriers were the unavailability of the family and the lack of support from medical personnel. Problems encountered with provision of consent and previous donation experiences have had a negative impact such that the donation process was not a positive experience with over 50% of respondents (either "discouraged" or "no effect").

The health profesionals felt that information in the form of literature, media, lectures and seminars and in-service education would be helpful stimuli to organ donation. A regional organ retrieval and exchange service and regular reminders regarding organ donation were also thought to be helpful. Thus, it is concluded that health care professionals are willing to respond to further information and there are several modes by which medical and administrative awareness can be enhanced.

A significant number felt that remuneration to the professional staff would be a helpful stimulus to organ donation. It is suggested that budget allocation directed to organ donation be provided to hospitals. In hospitals with a large number of potential donors, the government should hire an individual responsible for donation within that setting.

5.5 DISCUSSION SESSION

These findings were reviewed by a sub-committee of health care workers including physicians, nurses, technicians and transplant co-ordinators. The review by this committee produced the following recommendations:

1. Development of provincial standards for brain death:
   It was evident from the discussion that most of the participants felt the criteria for brain death should be standardized and applicable in all medical institutions in the province.

2. Development of an Organ Donor Procurement Committee for every hospital:

   It was felt that an Organ Procurement Committee located in each hospital would have the following functions:

   1. Develop donor criteria.
   II. Develop a policy for a routine "recorded consideration" of donation request for everyone with brain death.
   III. To establish an audit to determine if potential donors are not being converted to actual donors.

3. The Organ Donor Program should be a requirement for hospital accreditation:

   The discussion group agreed with the Committee report that an Organ Donor Committee should be established in each hospital. In order for a hospital to attain full accreditation, it must be evident that such a committee is operational.

4. Expand M.O.R.E. to co-ordinate all regional centres:

   The Multiple Organ Retrieval and Exchange Program currently serves all of Ontario. It was the sentiment of the discussion group that M.O.R.E. should be expanded in order to asssume the role of co-ordinating each regional centre. In fact, M.O.R.E. would be an umbrella structure for transplantation within the province.

5. Establishment of regional programs:

   It is suggested that regional programs be established in suitable areas within the province and that the purpose of these programs, in interaction with the local communities, is provision of the following:

   I. Education
   II. Easy access to system.
   III. Feedback system to donor hospitals and families.
   IV. Co-ordination of local needs with the Multiple Organ Retrieval and Exchange provincial program.

6. The development of a compensation program:

   The discusison committee felt that an incentive program to compensate hospitals, physicians and families for organ donation would increase the number of organ donors and decrease the present penalty experienced by hospitals and medical personnel when an organ is procured.

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ORGAN DONATION IN THE EIGHTIES

A BLUEPRINT FOR SUCCESS

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MINISTER'S TASK FORCE ON KIDNEY DONATION

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MINISTRY OF HEALTH
PROVINCE OF ONTARIO

TABLE OF CONTENTS

1.0 INTRODUCTION 93

2.0 OBJECTIVES 94

3.0 IDENTIFICATION AND ASSESSMENT OF POTENTIAL BARRIERS

3.1 Failure to Identify Potential Donors 94

3.2 Failure to Obtain Consent 97

3.3 Failure to Initiate the Donation Process with an Identified Donor 103

3.4 Failure to Properly Certify Brain Death 112

3.5 Failure to Adequately Maintain a Donor 113

3.6 Failure to Retrieve Donated Organs 113

4.0 DISCUSSION AND CONCLUSIONS

4.1 Failure to Identify Potential Donors 116

4.2 Failure to Obtain Consent 117

4.3 Failure to Initiate the Donation Process with an Identified Donor 118

4.4 Failure to Properly Certify Brain Death 119

4.5 Failure to Adequately Maintain a Donor 120

4.6 Failure to Retrieve Donated Organs 120

APPENDICES

APPENDIX 1 - Computer Search of Deaths in Ontario 1981-82, 1982-83 122

APPENDIX 2 - M.O.R.E. Program Reports, - 1976 - December 31, 1984 123

APPENDIX 3 - Gallup Poll on Organ Donation Conducted on Behalf of the National Kidney Foundation - Executive Summary 128

APPENDIX 4 - Canadian Gallup Pcll - 1978 vs 1983 130

APPENDIX 5 - Guideline for determination of brain death: The Canadian Society of Neurosurgery 131

1.0 INTRODUCTION

Once it has been determined by the attending medical staff that a patient appears suitable to be an organ donor, consent for organ removal is obtained from the next of kin. Either before or after the obtaining of consent, brain death must be declared by two physicians independent of the transplant team. One of these physicians may be the attending physician.

It should be noted that the protocol for the declaration of brain death is strictly set down and clearly defined. These guidlines apply to any patient who is brain dead and about to be removed from cardio-respiratory support systems, irrespective of whether they are potential organ donors. In Ontario, the addition of a second physician to the brain death certification process for the purpose of organ donation, and the recommendation that one of the physicians involved be a specialist in Neurology or Neurosurgery, adds further safeguards to the system. When patients are transferred to a transplant service for organ donation, the process of brain death certification is repeated at that centre prior to organ removal.

Following the certification of brain death and the obtaining of consent, the patient is maintained by continuous, intensive clinical and biochemical monitoring. Maintenance of vital signs is essential to ensure healthy organs for transplantation. When indicated, the coronor is notified and his permission to proceed with organ donation is obtained.

Arrangements are made with the Operating Room staff and surgeons for organ removal either in the donor centre or in the retrieval teams' centre if the donor is transferred. If multiple organ donation is to occur, retrieval teams for each organ are notified and mobilized so that removal of the organs occurs in the proper sequence. In the operating room, the kidneys and other organs are flushed with cold preserving solution and packaged in a sterile container to maintain hypothermia until a suitable recipient is identified and prepared for the transplant.

Although the donation process can break down at several stages, the critical point appears to occur in the Intensive Care Unit where, if a patient's condition is deteriorating, organ donation is either considered or not; once the process is initiated by the attending medical staff (or occasionally by the next of kin) organ donation usually proceeds without difficulty.

2.0 OBJECTIVES:

a) To study the steps involved in the organ donation process from the point of donor identification to the removal of the organs;

b) To identify barriers affecting this part of the donation process; and

c) To recommend suitable measures to overcome these barriers and thereby facilitate organ donation.

3.0 IDENTIFICATION AND ASSESSMENT OF POTENTIAL BARRIERS

3.1 FAILURE TO IDENTIFY POTENTIAL DONORS

a) A survey was conducted of all hospital deaths in the Province of Ontario in 1981/82 and 1982/83. Those deaths occurring as a result of illnesses that would be appropriate for organ donation were identified and grouped according to cause of death:

I. brain tumour
II. head trauma, brain injury, aneurysms, etc.;
III: asphyxia;
IV: poisoning

They were further divided into age groups:

1. (age 1 - 4)
2. (age 5 - 12)
3. (age 13 - 40) and
4. (age 41 - 65).

The number of deaths occurring within these age and illness categories was further delineated according to hospital group (Group 01 to 06, based on the number of treatment beds). The results of this study are detailed in Appendix 1.

In 1981 there were 219 kidneys available for transplantation and 204 kidney transplants were performed. An analysis of 34,694 deaths in Ontario during that period revealed that there were 1,179 potentially suitable donors (147 per million population) that could have provided 2,358 kidneys. 80% of these deaths occurred in Group 01 and 02 hospitals and 62% occurred in the Group 01 hospitals.

In 1982, 245 kidneys were available and 227 were transplanted. According to the analysis of 36,629 deaths in Ontario there could have been 1,383 donors (173 per million population) or 2,766 kidneys. Thus, 3.7% of all deaths were suitable as potential organ donors. Of these 72% were in Group 01 and 02 hospitals and 68% were in Group 01 hospitals.

There were similar findings in a study conducted in the United States by the Centre for Disease Control which showed, that when the age of potential donors studied was birth to 65, there were 116 potential donors per million population or almost 27,000 nationwide. However, in 1982 there were only 3,681 cadaveric kidneys transplanted.[1]

b) A survey of hospital charts was performed in a few selected hospitals in order to determine the number of missed organ donors. Deaths inappropriate for organ donation because of age or illness were excluded and the hospital charts of the remaining deaths were reviewed and a decision made as to whether these patients would have been suitable for organ donation.

This study was carried out at the Toronto General Hospital for 1981 and 1982, Sunnybrook Medical Centre for 1982, Kitchener-Waterloo for 1982, St. Joseph's and Civic Hospitals in North Bay for 1980 and 1981, Kingston General Hospital for 1981 and 1982, Grace Hospital in Windsor for 1982 and the Plummer Memorial Hospital in Sault Ste. Marie for 1982. The results of these analyses are presented in Table 1. In summary, the percentage of potentially suitable donors that were missed varied between 45% and 80%. This is consistent with the findings of similar studies in American centres. For example, a recent study in Minnesota reviewd 4,602 hospital deaths and found that of 71 potential donors only 28 became actual donors; ie. 60% were missed.[2]

Since the majority of potentially suitable donors are in Group 01 hospitals and because there is a potential for at least doubling organ donation rates, it would appear that attention should be concentrated on these centres for maximum results.

TABLE 1: SUMMARY OF HOSPITAL DEATHS: POTENTIAL VS. ACTUAL DONORS

		# DEATHS	POTENTIAL DONORS	ACTUAL DONORS	% MISSED
TORONTO GENERAL HOSPITAL	1981	1022	24 (2.3%)	13	45
	1982	1087	32 (3%)	18	44
SUNNYBROOK HOSPITAL	1982	746	31 (4.1%)	12	61
NORTH BAY CIVIC ST. JOSEPH'S HOSPITAL, NORTH BAY, ONTARIO	1980/81	8		2	75
KITCHENER-WATERLOO ST. MARY'S HOSPITAL	1982	148	9 (6%)	2	80
KINGSTON GENERAL	1981		8	2	75

c) Because the M.O.R.E. statistics (Appendix 2) reveal that the majority of donors occur as a result of motor vehicle accidents, a survey documented the number of fatal motor vehicle accidents by year in Ontario. There has been a progressive decline in this death rate probably as a result of seatbelt legislation and slower speed limits.

Because the majority of deaths occur at the accident scene or on the way to the hospital, the deaths were further divided to identify those that occurred after admission to hospital, most of which occur within the first week (Table 2).

TABLE 2: DEATHS SECONDARY TO MVA - ONTARIO

1973	1980	1981	1982	1983	
1,959	1,508	1,445	1,138	1,204	TOTAL DEATHS
		297	212	244	DEATHS AFTER ADMISSION

3.2 FAILURE TO OBTAIN CONSENT

Once a potential donor has been identified by either being certified as brain dead, or seen to be imminently becoming brain dead, consent must be sought from the relatives.

The person approaching the grieving relatives has a difficult task, and it is one with which he or she should be familiar and have some expertise. In surveying hospitals there was no clear group uniformly responsible for this task. Approximately 50% of doctors and nurses felt inhibited in initiating the donation process by "bothering" a grieving family for consent (Table 3).

TABLE 3: BOTHERING A GRIEVING FAMILY INHIBITS

	TRANSPLANT CENTRE	DIALYSIS CENTRE	OTHERS
NURSES	64	50	57
INT/RES.	47	50	50
NEUROSURG.		---- 39 ----	
ICU - M.D.	58	43	48
OTHER M.D.	71	38	48

In 1971 the Human Tissue Gift Act of Ontario was enacted allowing for organ donation from a heart beating donor at the time of death providing consent is obtained from the next of kin and that brain death has been determined by two physicians independent of the transplant team. Thus, in Ontario there is encouraged voluntarism in contrast to presumed consent which exists in several European countries. The organ donation rate has not been significantly altered in those countries adopting presumed consent as illustrated by France. (Tables 4,5)

TABLE 4: LEGAL ASPECTS: CONSENT

ENCOURAGED VOLUNTARISM:	Canada, U.S., U.K., Germany, Belgium, The Netherlands, Australia, New Zealand, Argentina, India, China, Japan, South Africa, South Korea, Thailand.
PRESUMED CONSENT:	Austria, Czechoslovakia, Denmark, Finland, France, Greece, Israel, Italy, Norway, Poland, Spain, Sweden, Switzerland.

TABLE 5: FRANCE: KIDNEY TRANSPLANTS

BEFORE	AFTER
1973 - 278	1978 - 550
1974 - 340	1979 - 613
1975 - 346	1980 - 667
1976 - 432	1981 - 714
1977 - 458	1982 - 850

Under present circumstances, the signed donor card on a licence acts as an assistance to the next of kin in determining the wishes of the deceased as they consider donation of their relative's organs. It was found during the Abt study on Public Attitudes to Organ Donation (re: Section IV Supplement) that people were upset to think that their provision for organ donation at the time of death could be overruled by their next of kin. It is exceedingly unlikely that, if the relatives are aware of the deceased wishes with respect to organ donation, they will overrule them. However, in the absence of any central registry and under the difficult circumstances of bereavement, it is unlikely that anyone will have information to assist the next of kin in making a decision.

It can be seen from the above that the public's attitude to organ donation and the ability to influence that attitude may have a profound effect on the availability of organs for transplant. In order to assess these factors, existing data was reviewed and new studies were initiated.

a) The results of the Gallup Poll conducted on behalf of the National Kidney Foundation in the United States (see Appendix 3 for the Executive Summary) state that almost 3/4 (72%) of those that were aware of organ transplants said that they would give permission to have the kidneys of a loved one donated after that person's death. Fifty percent said that they would likely donate their own child's kidneys in the event of an unexpected death, however, only 24% said that they would want their own kidneys donated after their death. Approximately 1 in 5 (20%) said that an important reason for not wanting their kidneys donated after death was "I never really thought about it". About the same proportion (20%) gave the reason for not donating as fear of mutilation. Only 7% stated that it was against their religion.

b) A comparison of a Canadian Gallup Poll in 1978 and 1983 concerned willingness to allow organ donation (Appendix 4). In 1978 12% of those questioned had signed however 41% had not signed but were willing to do so. In 1983 the percentage that had signed increased to 21% and those that had not but were willing had decreased to 38%.

c) Project report on Public Attitudes to Human Organ Donation by Abt Associates of Canada was commissioned on behalf of this Task Force and was designed to provide information for a potential advertising campaign directed to the Ontario public. Its objectives were to determine barriers and facilitators to kidney donation, understand reasons for family refusal to allow organ donation, and to investigate ways of motivating the public to achieve a larger supply of organs for transplantation. The study identified six major reasons for organs not being donated:

   i) Hastiness of organ removal and a feeling that the declaration of death and immediate subsequent organ removal interfered with the family's expression of grief;
   ii) Mutilation;
   iii) Fatalism and superstition;
   iv) Religion (Orthodox Jews and Jehovah Witnesses);
   v) Age (many people felt that they or their relatives would not be suitable donors unless they were very young); and
   vi) "I just never thought of it".

Those surveyed were very confused about the legal status of the signed donor card. Both those who had signed and not signed the drivers licence firmly believed that the next of kin should not be able to countermand the signed donor card. A number of those who had not signed their own organ donor card had not done so because they felt they were too old (over the age of 40) or too ill. Those who had signed their donor card, many of whom were over that age, felt that it should be left to the physicians to decide their suitability as donors. All respondents were uniformly opposed to the buying and selling of organs.

Many were surprised when they realized that there was no central registry of their wishes as expressed on the organ donor card, and felt that there should be such a registry. The European system, in which consent is presumed unless a card to the contrary is carried, was not felt to be acceptable in Canada. The concept of automatically becoming an organ donor in the event of brain death was rejected. Rather, respondents felt that publicity about the successes of transplantation and the need for donor organs would be valuable.

The committee carefully considered the possibility of a central registry based on the drivers licence in which all licenced drivers would be required to answer a question about post-mortem organ donation as either "yes, in favour", "no, opposed", or "I don't wish to answer". This data could be stored in a central computer to which ICU nurses and doctors would have 24 hour access. In its' considerations, the committee was aware of the figures quoted above which demonstrate that, although almost 80% of people would donate relatives' organs, only 24% would voluntarily donate their own. Thus, maintenance of such a compulsory registry might, in fact, decrease the available number of kidneys.

d) A poll conducted in early 1984 in Ontario concerned public attitudes towards donation. It was found that although the majority of people (85%) had heard of the vital organ donor card on Ontario drivers' licences, most of them (72%) had not signed it. Motivating people to sign the card appeared to be the key because it was found that 63% would likely donate their own kidneys upon death, 73% would likely donate their child's kidneys after a fatal accident, and 88% would donate kidneys of a relative. There was a strong correlation between hearing about signing the card and donation of organs.

e) A follow-up poll conducted in late 1984 to reassess the frequency of signed donor cards and to assess specific aspects of organ donation. Although 89.1% of the 1,000 people polled had heard of organ donor cards only 25.5% had signed one. Of those signing, 71% supported the donation of any organ required, whereas of the 80% of individuals in favour of donating relative's organs, only 51% indicated they would allow any organ required to be donated.

Support was high (68%) for the establishment of a central registry in which those having signed a donor card would be listed. However, there were differences regarding the most appropriate vehicle by which this registry would be formed. Of those indicating strong, somewhat or slight support for such a registry, 88.3% favoured utilizing the drivers' licence renewal form, 74.8% favoured an OHIP record and 59% suggested the Social Insurance Number. The majority of people (67.2%) felt that a relative should not be allowed to ignore the wishes of the deceased and overrule a signed donor card. As well, 75.8% felt that the signed organ donor card should be a legally binding document.

f) Medical experience with consent refusal by the next of kin of a potential donor was difficult to document. However 80% of health care professionals in transplant centres have had experience with the family refusing consent (Table 6) and over 90% of those surveyed in all hospitals identified the relatives as a significant barrier to organ donation (Table 7). There appears to be a need for further public education and encouragement to support organ donation in order to minimize the rate of consent refusal in the ICU.

TABLE 6: EXPERIENCE WITH FAMILY REFUSING CONSENT

	TRANSPLANT CENTRE	DIALYSIS CENTRE	OTHERS
NURSES	79	66	48
INT/RESIDENT	87	89	71
NEUROSURG.	----	93	----
ICU - M.D.	89	84	73
OTHER M.D.	100	79	70
TOTAL:	81	70	56

TABLE 7: BARRIERS TO ORGAN DONATION: INDIVIDUALS

	TRANSPLANT CENTRE	DIALYSIS CENTRE	OTHERS
RELATIVES	94	91	93
NURSES	20	31	27
INTERNS	20	26	24
RESIDENTS	26	28	23
NEPHROL/UROL.	13	24	25
ATTENDING M.D.	34	42	43
FAMILY M.D.	34	43	46
ADMINISTRATORS	30	32	36

3.3 FAILURE TO INITIATE THE DONATION PROCESS WITH AN IDENTIFIED DONOR

The vast majority of potential donors are in intensive care units of secondary and tertiary hospitals (Appendix 1). The majority of actual donors come from the nine transplant centres and to a lesser extent the other tertiary care and some secondary care hospitals. It is almost certain that attitudinal and practical barriers affect the performance of the professionals working in these units with respect to their roles as initiators of the donation process. In order to study these barriers, a survey of intensive care unit staff, both medical and nursing, in addition to Chaplains, Neurologists, and Neurosurgeons was conducted by Burton and Associates*. In addition, hospital administrators were asked to complete a questionnaire with respect to administrative structure concerning organ donation in their institutions.

* NOTE: Further research has been conducted and final data are available. Address any enquiries to: Dr. H. Burton, Department of Psychiatry, Toronto Western Hospital, 399 Bathurst Street, Toronto, Ontario.

A total of 102 from 118 hospitals with ICU's responded representing an 86.4% return rate. Of the 2,116 questionnaires distributed to the ICU staff, 2,024 were returned (95% return rate). 33 Neurosurgeons (55%) and 45 neurologists (35%) returned the questionnaire (Table 8).

TABLE 8: RESPONDENTS POSITION IN THE HOSPITAL

NURSES	-	1479	(73%)
INT/RES.	-	55	(3%)
NEUROSURG.	-	33	(2%)
ICU - M.D.	-	119	(6%)
OTHER M.D.	-	251	(12%)
CHAPLAIN	-	87	(4%)
		2024	

From an analysis of the administrative respondents, the following was noted:

a) Only 46% of hospitals have written policies regarding organ donation.

b) Only 28% have a designated individual or team responsible for dealing with the organ donation process.

c) A significant number of hospital administrators perceive lack of interest on the part of their medical staff or boards as a barrier to involvement in the organ donation process; 40% of responding administrators reported no involvement of their institution in the process and many were unaware of how the process worked.

d) 85% of administrators felt that they could improve their contributions to organ donation with outside help and direction, and 62% felt that financial reimbursement for expenses of organ donation would increase the yield.

From an analysis of the responses of the ICU staff, Neurologists and Neurosurgeons, experience with previous potential kidney donors varied according to the respondents' position and type of hospital (Table 9). Most respondents were aware of a number to call for advice concerning a potential donor (Table 10) and most often this number was the M.O.R.E. program. The attending physician was the most likely person to initiate the donation process but others such as nurses, residents, and sometimes relatives were also seen as fulfilling this role (Table 11).

TABLE 9: PAST EXPERIENCE WITH POTENTIAL KIDNEY DONORS

	TRANSPLANT CENTRE	DIALYSIS CENTRE	OTHER
NURSES	83	54	37
INT/RES	89	90	52
NEUROSURG.		---- 100 ----	
ICU - M.D.	86	87	52
OTHER M.D.	64	80	49
TOTAL:	82	60	40

TABLE 10: NUMBER TO CALL FOR ADVICE RE: ORGAN DONATION

	TRANSPLANT CENTRE	DIALYSIS CENTRE	OTHER
NURSES	64	67	52
INT/RES	61	67	48
NEUROSURG.		---- 72 ----	
ICU - M.D.	86	87	48
OTHER M.D.	71	73	58
TOTAL:	71	70	59

TABLE 11: WHO INITIATES THE DONATION PROCESS

		TRANSPLANT CENTRE	DIALYSIS CENTRE	OTHERS
ATTENDING M.D.	NURSES	77	51	32
	INT/RES.	94	80	42
	NEUROSURG.		---- 84 ----	
	ICU - M.D.	90	77	41
	OTHER M.D.	71	47	50
SOMETIMES USUALLY ALWAYS	NURSES	50	51	28
	INTERN	40	40	19
	RESIDENT	80	57	25
	ATTENDING M.D.	78	54	37
	RELATIVE	39	30	19

The following problems were identified which contribute to medical barriers in the organ donation process:

a) Most hospitals do not have a clear policy facilitating organ donation and as a result there is confusion by both doctors and nurses as to procedures involved with a potential organ donor (Table 12).

b) Another medical barrier is that the organ donation process is extremely time consuming and disruptive, particularly for physicians and nurses who are busy supervising the care of other critically ill patients in the Intensive Care Unit. Approximately 3/4 of doctors and nurses in all hospitals stated that the time demand is a barrier to participating in the organ donation process (Table 13).

TABLE 12: BARRIERS TO ORGAN DONATION

		TRANSPLANT CENTRE	DIALYSIS CENTRE	OTHERS
LACK OF CO-ORDINATION	NURSES	81	79	92
	INT/RES.	66	80	76
	NEUROSURG.		---- 73 ----	
	ICU - M.D.	42	65	87
	OTHER M.D.	70	73	82
	TOTAL:	76	78	89

TABLE 12: BARRIERS TO ORGAN DONATION (CONTINUED)

		TRANSPLANT CENTRE	DIALYSIS CENTRE	OTHERS
NO FIRM GUIDELINES	NURSES	70	71	91
	INT/RES.	78	80	76
	NEUROSURG.		---- 48 ----	
	ICU - M.D.	43	65	79
	OTHER M.D.	64	73	79
	TOTAL:	69	72	86
NO CLEAR LINES OF RESPONSIBILITY	NURSES	75	78	93
	INT/RES.	72	80	83
	NEUROSURG.		---- 42 ----	
	ICU - M.D.	62	61	72
	OTHER M.D.	71	73	83
	TOTAL:	74	76	88

TABLE 13: BARRIERS TO ORGAN DONATION: TIME DEMAND OF THE DONATION PROCESS

	TRANSPLANT CENTRE	DIALYSIS CENTRE	OTHERS
NURSES	74	71	82
INT/RES.	66	70	75
NEUROSURG.		---- 82 ----	
ICU - M.D.	71	70	79
OTHER M.D.	93	73	75
TOTAL:	73	71	80

c) Two-thirds of doctors and 82% of nurses in non-transplant hospitals without a dialysis unit felt that a significant barrier is a lack of an in-hospital team or individual assigned to the donation process (Table 14). The responses were lower in the transplant centres because most have such an individual identified (Table 14,15).

TABLE 14: STATEMENT RE ORGAN DONATION: PROBLEM IS ABSENCE OF IN-HOSPITAL TEAM/INDIVIDUAL

	TRANSPLANT CENTRE	DIALYSIS CENTRE	OTHERS
NURSES	58	73	82
INT/RES.	33	80	61
NEUROSURG.		---- 44 ----	
ICU - M.D.	32	48	68
OTHER M.D.	78	50	63
TOTAL:	55	69	79

TABLE 15: WHOM TO CALL FOR ASSISTANCE FOR ORGAN DONOR

		TRANSPLANT CENTRE	DIALYSIS CENTRE	OTHERS
UROLOGIST	NURSES	62	70	75
	INT/RES.	77	78	76
	NEUROSURG.		---- 80 ----	
	ICU - M.D.	87	87	72
	OTHER M.D.	100	100	82
TRANSPLANT CO-ORDINATORS	NURSES	80	48	28
	INT/RES.	60	37	50
	NEUROSURG.		---- 67 ----	
	ICU - M.D.	78	36	19
	OTHER M.D.	82	40	28

d) Another problem identified was the lack of specific information concerning suitability for organ donation and optimal donor maintenance. Significant numbers of both physicians and nurses showed limitations in their knowledge of who constitute appropriate organ donors.

e) The majority (approximately 90%) of those surveyed identified the need for more lectures, written information and in-service training (Table 16) and most recognized that a lack of familiarity with the donation process is a significant barrier (Table 17).

TABLE 16: ALTERNATIVES TO PROMOTE AWARENESS

	TRANSPLANT CENTRE	DIALYSIS CENTRE	OTHERS
LITERATURE TO STAFF	88	95	95
LECTURES, IN SERVICE	93	94	94
MEDIA	81	84	88
REGULAR CALLES TO ICU - NURSES	41	60	47
- MDs	14	14	46
INCREASED REMUNERATION - INT/RES.	13	10	54
- ICU - M.D.	9	26	40
- OTHER M.D.	38	52	32
REGIONAL ORGAN RETRIEVAL AND EXCHANGE PROGRAM	89	92	91

TABLE 17: BARRIERS TO ORGAN DONATION: LACK OF FAMILIARITY WITH PROCESS

	TRANSPLANT CENTRE	DIALYSIS CENTRE	OTHERS
NURSES	79	86	95
INT/RES.	72	90	85
NEUROSURG.		---- 48 ----	
ICU - M.D.	57	83	84
OTHER M.D.	71	84	85
TOTAL:	76	85	92

f) Financial considerations were also identified by the survey. The possible effect of improved remuneration to physicians participating in the donation process is difficult to document because of the reluctance of doctors to admit that inadequate payment (compared to time and effort expended) might be contributing to the current donor shortage. The lack of adequate remuneration was perceived as a barrier with approximately 1/4 of ICU MDs in transplant and dialysis centres but this number increased to approximately 50% with other physicians in those centres. As well "other" centres had a similar percentage of both ICU MDs and other MDs reporting inadequate remuneration as a barrier (Table 18). Non-transplant hospitals without dialysis units perceived the organ donation process as possibly creating a financial burden to their ICU hospital budget (Table 19).

TABLE 18: BARRIERS TO ORGAN DONATION: LACK OF ADEQUATE REMUNERATION

	TRANSPLANT CENTRE	DIALYSIS CENTRE	OTHERS
NURSES	41	53	55
INT/RES.	12	11	65
NEUROSURG.		---- 41 ----	
ICU - M.D.	28	24	57
OTHER M.D.	50	48	51
TOTAL:	38	47	56

TABLE 19: BARRIERS TO ORGAN DONATION: FINANCIAL BURDEN TO I.C.U.

	TRANSPLANT CENTRE	DIALYSIS CENTRE	OTHERS
NURSES	41	55	64
INT/RES.	44	44	60
NEUROSURG.		---- 33 ----	
ICU - M.D.	33	35	57
OTHER M.D.	50	50	51
TOTAL:	40	53	61

g) Over 70% of physicians (but only 36% of neurosurgeons) and more than 80% of nurses felt that questions of legal responsibility were at least some barrier to the initiation of the donation process (Table 20).

h) Certain contradictions were noted in the analysis of responses (Table 21). Over 90% of respondents recognized the need for organ donors and realized that they had a role in the organ donation process including its' initiation. The majority of nurses and doctors felt a professional responsibility to initiate the donation process and yet a significantly lower percentage of ICU and other MDs (including the neurosurgeons) in the other centres responded that they would initiate the donation process. Personal feelings towards organ donation acts as a barrier with approximately 1/2 of respondents as they felt inhibited in initiating the process by "bothering" a grieving family for consent.

TABLE 20: BARRIERS TO ORGAN DONATION: LEGAL FACTORS

	TRANSPLANT CENTRE	DIALYSIS CENTRE	OTHERS
NURSES	72	79	84
INT/RES.	61	70	72
NEUROSURG.		---- 36 ----	
ICU- M.D.	57	64	88
OTHER M.D.	78	73	70
TOTAL:	78	77	80

TABLE 21: CONTRADICTIONS

	TRANSPLANT CENTRE	DIALYSIS CENTRE	OTHER
NEED FOR MORE DONORS	99	99	99
ROLE IN ORGAN DONATION	92	96	93
INITIATE DONATION PROCESS	82	87	88
PROFESSIONAL RESPONSIBILITY TO INITIATE DONATION PROCESS			
NURSES	65	72	75
INT/RES.	88	100	92
NEUROSURG.		---- 88 ----	
ICU - M.D.	95	95	82
OTHER M.D.	93	88	88
WOULD HELP INITIATE DONATION PROCESS			
NURSES	77	83	84
INT/RES.	82	90	74
NEUROSURG.		---- 55 ----	
ICU - M.D.	55	77	88
OTHER M.D.	53	80	74
WOULD LIKE TO GET INVOLVED IN ORGAN DONATION PROCESS			
NURSES	67	79	79
INT/RES.	61	100	80
NEUROSURG.		---- 32 ----	
ICU - M.D.	60	73	72
OTHER M.D.	79	76	71
PERSONAL FEELINGS A BARRIER			
NURSES	53	52	50
INT/RES.	50	50	36
NEUROSURG.		---- 27 ----	
ICU - M.D.	47	18	20
OTHER M.D.	43	38	27

In an effort to complement the study of Professional Barriers to Human Organ Donation by Burton and Associates and to validate some of their results, in-depth individual interviews of physicians, nurses and clergy have occurred in three selected hospitals (the Kingston General Hospital, the Toronto General Hospital and the Grace Hospital in Windsor). This study entitled "Professional and System Barriers to Organ Donation" was conducted by Sue Corlett and is summarized in the Abt research summary (re: Section IV Supplement). Because the potential and actual organ donation rates have already been documented, these hospitals will also serve as models to measure the effects of implementation of the Task Force's recommendations.

3.4 FAILURE TO PROPERLY CERTIFY BRAIN DEATH

It is essential for successful renal transplantation that the kidneys are adequately perfused until the moment they are removed. Thus, appropriate donors are only those in whom the death of the brain has occurred in the presence of continuing cardiac function and artificial respiratory support. Certification of death in such a patient is very different from the more common circumstance in which heart and circulation fail. Certification of death by this method is by no means unique to the donor patient. However, due to the nature of the diseases involved, it has commonly been specialists in Neurology and Neurosurgery who have been responsible for certification of brain death. It is therefore not surprising that large segments of the medical community are both unfamiliar and uncomfortable with the procedures for certification of brain death.

Indeed, enquiry of those responsible for the curriculum in Ontario's medical schools failed to identify any clear responsibility for this area of medical education. In spite of this, there are clearly defined protocols, procedures and criteria for the certification of brain death. Such a protocol is presented in Appendix 5. However, enquiry suggests that these protocols are not immediately available in all hospitals, and particularly not in those which lack a Neurologist or

Neurosurgeon on staff. The general unfamiliarity and discomfort that physicians in smaller centres frequently feel with respect to certification of brain death may significantly inhibit their involvement in the donation process.

All transplant centres insist that two physicians certify brain death and, as a rule, one will be a neurologist or neurosurgeon. It is the policy of all transplant centres that non-living donors transferred to them for organ donation be recertified as brain dead prior to organ removal.

3.5 FAILURE TO ADEQUATELY MAINTAIN A DONOR

Once a donor has been identified, certified brain dead and consent for donation has been obtained, the donor must be maintained in a stable condition until the organs are removed. The quality of the kidneys and their functional survival in the recipient, and therefore the recipient's subsequent health, are determined at least in part by the adequacy of donor maintenance. This task is difficult, expensive, time-comsuming and at present unrewarded. Many institutions with identified donors lack both clear guidelines and the trained personnel necessary to maintain the vital signs until arrangements can be made for organ removal.

3.6 FAILURE TO RETRIEVE DONATED ORGANS

The majority of potential donors are found in Group 01 and 02 hospitals (Appendix 1). The majority of actual donors arise from transplant centres which act as regional retrieval centres. A significant number at present and a potentially greater number of donors in the future could be provided by non-transplant centres. The alternatives available for these centres are 1) to make use of local teams to retrieve the kidneys, 2) to dispatch a team to the donor hospital; or 3) to transfer the donor to the regional retrieval unit centre. Options (1) and (3) appear to be the preferred course. In the experience of the M.O.R.E. program with over 1600 kidneys donated over the past 8 years, there have been only 5 instances in which the Toronto retrieval team has been dispatched to a peripheral centre even though the team has been widely publicized and has been available on a 24 hour on-call basis. Furthermore, of approximately 800 donors only 40 were transferred from a peripheral centre to one of the transplant centres for the purpose of organ donation.

The present organ retrieval system in Ontario has developed over the past 9 years. In 1976 the Metro Organ Retrieval and Exchange (M.O.R.E.) program was established as a collaborative effort between the four Toronto transplant centres (Toronto General Hospital, Toronto Western Hospital, St. Michael's Hospital and the Hospital for Sick Children) in order to increase the supply of kidneys and other organs for transplantation. Within two years Ottawa (Ottawa Civic and the Ottawa General Hospital), Kingston (The Kingston General Hospital), Hamilton (St. Joseph's Hospital) and London (University Hospital) joined thereby making it a provincial program. A 24 hour on-call retrieval team was formed to provide telephone advice to donor centres, to arrange for transfer of a potential donor to the retrieval team's hospital or to call for the retrieval team to travel to the donor centre for removal of organs. All hospitals in the Province were contacted and encouraged to participate in the Organ Donor Program and pamphlets were provided outlining suitability for organ donation and guidelines for donor maintenance. Talks and seminars have been given to the medical and nursing staff of many Ontario hospitals and programs promoting organ donation by the public have been undertaken.

The M.O.R.E. program has been collecting data concerning various aspects of organ donation since 1976 such as where the kidneys were transplanted including graft and patient survival rates. This information is updated and discussed at the M.O.R.E. meeting held three times each year. The M.O.R.E. committee is composed of surgeons and nephrologists from each of the participating hospitals. In addition to reviewing data, decisions are made regarding policy and collabortative clinical trials. Recently, the name of the program has been changed to Multiple Organ Retrieval and Exchange and representatives from the non-renal transplant programs have been invited to become committee members.

Each participating city is responsible for organ retrieval in their city and surrounding area. Thus, London covers Southwestern Ontario, Toronto services Central and Northern Ontario (with the exception of Hamilton which is on call for the Niagara Peninsula), and Ottawa and Kingston cover Eastern Ontario. These regional programs require appropriate funding for their activities including a regional organ retrieval co-ordinator, public relation activities and local data collection.

Besides co-ordinating organ retrieval in Toronto and Northern and Central Ontario, the personnel of the M.O.R.E. program are responsible for locating suitable recipients in other parts of Canada or the United States for kidneys and other organs than cannot be transplanted in Ontario. To facilitate this, the M.O.R.E. computer has listed all patients across Canada who are waiting for renal and non-renal transplants. When kidneys are offered from other Canadian or American centres to the M.O.R.E. program, appropriate recipients are located with the use of the computer. Kidneys on perfusion are accompanied by a perfusionist to the recipient transplant centre. The perfusionists are also responsible for collecting all of the data related to organ donation in Ontario as well as following up on the outcome of the transplant both in the short and long term. With each organ donor, personal letters of thanks and appreciation are sent to the donor's family as well as the doctors and nurses who participated in the organ donation.

The current M.O.R.E. program has a staff of 6 including 1 secretary, 1 co-ordinator, 1 statistician, and 3 perfusionists, one of whom is directing most of her time to public relations. The annual budget is $384,000 of which $186,000 is for salaries and $120,000 for supplies (perfusion equipment and solutions).

4.0 DISCUSSION AND CONCLUSIONS

The steps by which a terminally sick patient identified as a potential donor is converted into an actual donor are referred to as the "donation process". It involves the introduction of the concept of organ donation to the patient's family, the request for donation, the signing of consent, the certification of brain death, and the obtaining of the Coroner's consent. The donor must be maintained in stable clinical condition both before and after the declaration of brain death. Following the declaration of brain death and the obtaining of consent, the organization of the operating room staff, anaesthetists, and single or multiple organ retrieval teams is required. These teams are either dispatched to the donor centre, if they are not already there, or the patient is transported to the transplant centre. Following retrieval, organ preservation is performed prior to distribution and transplantation.

4.1 FAILURE TO IDENTIFY POTENTIAL DONORS

The evidence suggests that at least 50% of the donors in large hospitals are not being identified as potential donors or, if identified, are not being converted to actual donors. It should therefore be possible to double the supply of kidneys from these large tertiary care hospitals. It also appears that a small but not insignificant number of potential donors are failing to be identified in the secondary hospitals.

An intensive program of education, concentrated on the secondary and tertiary care hospitals to increase awareness of the potential organ donor, appears to be required. The vehicle for such educational efforts should be an Organ Donation Committee established in each hospital to supervise organ donation. This would involve provision of protocols for identification and organ retrieval performance. Endorsement by the Ontario Hospital Association and the provision of appropriate guidelines for these committees would be of value.

As well, increased and ongoing public education and promotion of organ donation by a professional marketing firm (to include transit ads, billboards, radio and TV commercials and inserts with the renewed drivers' licence encouraging signing) is suggested in order to change public attitudes towards organ donation and transplantation.

4.2 FAILURE TO OBTAIN CONSENT

The person seeking consent will probably vary from institution to institution; however, each hospital should have a clear policy with respect to the responsibility, and timing of a request, for organ donation. Although in theory legally binding, the signed donor card is usually not available at the crucial time; however, when available it serves to assist the next of kin in their decision-making process. Also, the driver's licence signing program is a definite benefit as an educational aid.

The public generally feels positive towards organ donation as over 80% are willing to donate the organs of a deceased relative. Substantially fewer are willing to donate their own organs which probably represents their reluctance to admit their own mortality. There is opposition to presumed consent, mandatory donation and to any form of commerce in organ donation.

There is a need for ongoing public education concerning the successes of transplantation and the need for donor organs. This should be accomplished by promoting the drivers' licence and other organ donor card signing programs. The establishment and maintenance of a system to record one's intention to donate organs at the time of death is proposed. This could be accomplished by forming a central registry using a data bank such as the computer at the Ministry of Transportation and Communications which could be accessed 24 hours a day.

4.3 FAILURE TO INITIATE THE DONATION PROCESS WITH AN IDENTIFIED DONOR

It is apparent that there are several professional barriers to initiating the donation process and that consequently several changes are required in order to effect an improvement in the supply of organs for transplantation. It is encouraging to note that health care professionals hold positive attitudes towards the donation process and should respond to appropriate measures to increase their involvement. The following procedures are suggested:

a) All hospitals should have a clear policy facilitating donation with guidelines for the medical staff. It would be optimal if a recommended set of guidelines endorsed by the OHA would be provided to each hospital to ensure uniformity. Guidelines would concern: consent forms and methods of obtaining consent, declaraction of brain death, policy regarding donor transportation, temporary operating privileges for retrieval teams from other hospitals and provision of a designate to organize and coordinate the donation process.

b) Designation of an Organ Donation Committee in each hospital in order to appoint a donation coordinator and to implement clear guidelines that would facilitate donation within each institution. Donation coordinators would function as resource people in all aspects of the donation process including donor maintenance, assistance with relatives, maintenance of records and audit function as well as education. The specific relationship between the donation coordinator and the committree would vary depending on the institution.

c) A central organization such as the Multiple Organ Retrieval and Exchange (M.O.R.E.) program should take the responsibility of preparing guidelines for distribution to all provincial hospitals concerning organizational structure, educational requirements, identification and maintenance of potential donors and protocols for organ removal and initial preservation.

d) In order to maintain medical and nursing staff awareness of the need for transplantable organs, continuing medical education is essential. This should be accomplished via medical staff meetings, nursing in-service sessions and reminders in medical and nursing journals. As with public education, this must be an ongoing process and should focus on the success of organ transplantation, the critical shortage of organs and the important role of medical staff in the donation process. In teaching hospitals, the residents and interns should be reminded about protocols and procedures involved in donation when they change services.

e) Hospital clergy should be encouraged to be part of the team to provide spiritual and moral support to the next of kin. In some centres pastoral services have played a particularly active role resulting in an increased number of organ donations (e.g. Kitchener-Waterloo and Sunnybrook Hospitals).

f) Consideration should be given to recognize financially the contribution by institutions and individuals to the organ donation process.

4.4 FAILURE TO PROPERLY CERTIFY BRAIN DEATH

The procedures and criteria for the certification of brain death are clearly defined. Many non-neurological physicians and surgeons are uncomfortable with these procedures and therefore are reluctant to declare brain death. Therefore, an individual or team should be designated in each hospital to perform organ donor assessment if requested by the staff of the Emergency Department or Intensive Care Unit. This difficulty could also be overcome by encouraging donor transfer to transplant centres where brain death certification can be more easily performed with the aid of special equipment when indicated.

It would appear to be helpful to distribute to all provincial hospitals clearly acceptable guidelines, procedures and criteria for the certification of brain death. Such distribution would occur under the auspices of a central organization such as M.O.R.E. As well, regular audits of hospital deaths and organ donation should occur. Further contact with medical schools regarding this aspect of education should occur as well as further educational efforts by organ donation committees or donation coordinators within each hospital.

4.5 FAILURE TO ADEQUATELY MAINTAIN A DONOR

Guidelines for donor maintenance should be provided to every provincial hospital through the educational effort of a central organization such as M.O.R.E. working with the Organ Donation Committees and coordinators. M.O.R.E. pamphlets are currently available and have been distributed several times. However, they tend to be eventually misplaced and therefore redistribution is necessary on a regular basis.

A 24-hour telephone number that is currently available through M.O.R.E. (1-800-387-LIFE) should continue to provide advice concerning problems encountered with organ donation in the province, and at least one retrieval team should be available to assist with or perform organ removal in peripheral centres. It is also concluded that improved remuneration for physicians identifying appropriate donors and participating in the activities of the organ donor assessment team be provided.

4.6 FAILURE TO RETRIEVE DONATED ORGANS

The Regional Organ Retrieval Programs in Ottawa, Kingston, Hamilton and London require further support and funding for the costs involved in the regional retrieval activities. Each transplant program requires a coordinator as well as computer facilities to store and analyze local data. Thus each program will be supported for maximal efficiency of organ procurement.

A central organization such as M.O.R.E. should continue to function as a 24-hour coordinating body of the regional retrieval and distribution of all organs. Additional responsibilities would include the review and recommendation of technical standards and the maintenance of statistics.

REFERENCES

1. Bart KJ, Macon EJ, Whittier FC, et al: Transplantation 31: 379, 1981

2. Carlson D, Hellerstedt W, Anderson J, et al: Transplant Proc 17: 99, 1985

APPENDIX I

COMPUTER SEARCH OF 34,694 DEATHS IN ONTARIO 1981-82

HOSPITAL GROUP	4I	4II,III,IV	3I	3II,III,IV	2,1	TOTAL
GROUP 01	66	406	16	154	91	733
GROUP 02	29	150	1	25	7	212
GROUP 03	20	53	4	14	4	95
GROUP 04	16	43	1	11	0	71
GROUP 05	26	17	5	3	0	51
GROUP 06	3	13	0	0	1	17
TOTAL:	160	682	27	207	103	1179

COMPUTER SEARCH OF 36,629 DEATHS IN ONTARIO 1982-83

HOSPITAL GROUP	4I	4II,III,IV	3I	3II,III,IV	2,1	TOTAL
GROUP 01	83	498	28	294	39	942
GROUP 02	37	90	6	27	4	164
GROUP 03	21	48	4	7	1	81
GROUP 04	43	64	2	19	3	131
GROUP 05	17	34	2	3	1	57
GROUP 06	2	5	0	0	1	7
TOTAL:	203	739	42	350	49	1383

LEGEND:

A.
- I Brain Tumors
- II Head Trauma, Brain Injury Aneurysms, Etc.
- III Asphyxia
- IV Poisoning

B.
- 1 = Age 1 - 4
- 2 = Age 5 - 12
- 3 = Age 13 - 40
- 4 = Age 41 - 65

Group 01 - OCATH Hosps.
Group 02 - 400+ Beds, All levels of care.
Group 03 - 200-399 Beds, with long term care.
Group 04 - 200-399 Beds, no long term care.
Group 05 - 100-199 Beds, with long term care.
Group 06 - 100-199 Beds, no long term care.

GROUP 01
Hamilton Chedoke McMaster
Hamilton Civic
Hamilton St. Joseph's
Kingston General
Kingston Hotel Dieu
London St. Joseph's
London University
London Victoria
Ottawa CHEO
Ottawa Civic
Ottawa General
Toronto Mount Sinai
Toronto Sick Children's
Toronto St. Michael's
Toronto General
Toronto Western
Toronto Wellesley
Toronto Women's College
Toronto Sunnybrook

GROUP 02
Belleville General
Brampton Peel Memorial
Burlington Jos Brant
Kitchener-Waterloo
Mississauga Hospital
Oshawa General
Owen Sound General and Marine
Peterborough Civic
St. Catharines General
Toronto St. Joseph's HCTR
Toronto East General
Toronto Etobicoke General
Toronto North York General
Toronto Scarb. Centenary
Toronto Scarb. General
Windsor Hotel Dieu
Windsor Metropolitan
Windsor Western IODE
Windsor Western RIVR

APPENDIX 2

MULTIPLE ORGAN RETRIEVAL AND EXCHANGE (M.O.R.E.) STATISTICAL REPORTS 1976-1984

AVAILABILITY OF KIDNEYS FOR TRANSPLANTATION

	1977		1978		1979		1980		1981		1982		1983		1984	
	A	TX	A	TX	A	TX	A	TX	A	TX	A	TX	A	TX	A	TX
JAN	8	7	11	9	19	18	21	17	23	21	19	18	9	8	20	19
FEB	10	10	16	16	18	15	15	14	25	18	12	11	4	4	21	21
MAR	21	14	10	9	18	16	18	16	10	10	18	18	16	12	19	17
APR	9	8	20	18	4	4	23	22	18	17	19	19	18	18	27	23
MAY	10	10	11	10	5	5	29	29	18	18	25	24	27	25	26	24
JUNE	24	23	16	13	14	14	14	12	18	17	21	18	31	30	26	26
JULY	14	7	20	17	22	21	24	20	19	18	32	29	20	19	22	22
AUG	17	16	22	16	23	23	4	3	25	25	32	29	31	28	26	25
SEPT	23	21	18	16	27	23	22	20	25	24	20	19	26	23	10	10
OCT	26	20	21	17	13	11	8	7	7	6	14	13	16	15	29	27
NOV	20	18	12	12	15	14	13	13	20	20	18	16	25	25	31	28
DEC	9	8	11	5	17	13	21	21	15	14	15	13	26	23	24	23
TOTAL	191	162	188	158	195	177	212	194	223	208	245	227	249	230	281	265

AVERAGE TRANSPLANTS PER MONTH

1977 - 13.5	1981 - 17.3
1978 - 13.1	1982 - 18.9
1979 - 14.7	1983 - 19.1
1980 - 16.1	1984 - 22.0

JUNE 1, 1976 TO DECEMBER 31, 1984

TOTAL KIDNEYS AVAILABLE	1844
TRANSPLANTED	1678 (90.99%)
RESEARCH	166 (9.00%)

DISTRIBUTION OF DONORS
JUNE 1, 1976 TO DECEMBER 31, 1984

KIDNEYS FROM:

TORONTO	809	(43.8)
LONDON	293	(15.8)
ONTARIO	197	(10.6)
HAMILTON	158	(8.5)
OTTAWA	134	(7.2)
QUEBEC	82	(4.4)
U.S.A.	62	(3.3)
KINGSTON	50	(2.7)
MANITOBA	21	(1.1)
NEWFOUNDLAND	14	(0.7)
ALBERTA	12	(0.6)
NEW BRUNSWICK	7	(0.3)
NOVA SCOTIA	3	(0.1)
SASKATCHEWAN	2	(0.1)

DISTRIBUTION OF ONTARIO DONORS
JUNE 1, 1976 TO DECEMBER 31, 1984

KITCHENER-WATERLOO	64
SUDBURY	44
THUNDER BAY	24
WINDSOR	17
ST. CATHARINES	16
NORTH BAY	6
SAULT STE. MARIE	6
PETERBOROUGH	4
NIAGARA FALLS	4
BURLINGTON	2
CORNWALL	2
KIRKLAND LAKE	2
OSHAWA	2
PARRY SOUND	2
YORK CENTRAL	2
TOTAL:	197

DISTRIBUTION OF TORONTO DONORS

JUNE 1, 1976 TO DECEMBER 31, 1984

KIDNEYS FROM TRANSPLANT CENTRES:

TORONTO GENERAL		251
TRANSFERRED INTO TGH:		50
OSHAWA	4	
SCARBOROUGH	10	
MT. SINAI	2	
BARRIE	2	
PETERBOROUGH	4	
NORTH YORK	2	
MISSISSAUGA	4	
ETOBICOKE	2	
QUEENSWAY	2	
EAST GENERAL	4	
THUNDER BAY	2	
ST. JOSEPH'S	2	
ENGLEHART	2	
YORK CENTRAL	2	
HUMBER MEMORIAL	2	
NORTH WESTERN	4	
HSC		95
SMH		119
TWH		118

KIDNEYS FROM NON-TRANSPLANT CENTRES:

SUNNYBROOK	128
WELLESLEY	38
YORK FINCH	2
HUMBER MEMORIAL	4
MT. SINAI	4

AGE BREAKDOWN OF DONORS IN THE M.O.R.E. PROGRAM

AGE GROUP	MALE	FEMALE	TOTAL
0 - 15	98	65	163
16 - 20	130	63	193
21 - 30	171	77	248
31 - 40	80	77	157
41 - 50	68	67	135
51 - 60	35	30	65
60	3	12	15
TOTAL:	585	391	976

CAUSES OF DEATH OF DONORS IN THE M.O.R.E. PROGRAM

CAUSE OF DEATH	M	F	MALE	FEMALE	TOTAL
BRAIN DAMAGE:			553	360	912
M.V.A.	256	111			
SUBARACHNOID & SUBDURAL HAEMATOMA	131	163			
ANEURYSM	24	22			
GUNSHOT	51	5			
HYPOXIA - (CARDIAC & RESP. ARREST)	29	36			
OTHER	62	23			
OVERDOSE			12	12	24
BRAIN TUMORS			8	10	18
OTHER			10	10	20
		TOTAL:	583	392	975

KIDNEYS FROM DONOR CENTRES

JUNE 1, 1976 TO DECEMBER 31, 1984

	TGH	LON	HAM	SMH	TWH	HSC	K-W	OTT	KIN	OTH
1976	12	14	1	4	4	6	1	0	0	18
1977	30	38	17	13	14	10	11	4	1	53
1978	46	31	28	12	6	4	10	13	2	36
1979	45	11	13	7	16	15	5	2	7	74
1980	35	36	10	11	12	3	7	15	9	74
1981	24	46	18	16	18	8	6	21	3	63
1982	35	48	21	16	10	16	4	20	4	71
1983	22	36	26	14	15	17	10	23	14	72
1984	50	33	24	26	23	16	10	36	10	53

DISTRIBUTION OF KIDNEYS

JUNE 1, 1976 TO DECEMBER 31, 1984

	TGH	TWH	SMH	HSC	LON	HAM	KIN	GEN	CIV	OTH
1976	18	15	8	9	2	0	0	0	0	5
1977	29	24	25	17	18	9	0	5	3	32
1978	28	32	18	19	11	18	0	1	2	29
1979	32	40	18	16	19	19	4	1	3	25
1980	14	45	23	31	16	14	8	7	10	26
1981	28	49	24	21	16	21	7	7	7	28
1982	41	49	24	21	25	20	5	6	7	29
1983	40	42	31	26	32	25	6	8	13	7
1984	41	44	30	22	40	31	6	19	14	18

APPENDIX 3

GALLUP POLL ON ORGAN DONATION CONDUCTED ON BEHALF OF THE NATIONAL KIDNEY FOUNDATION - EXECUTIVE SUMMARY

AWARENESS OF ORGAN TRANSPLANTS IS HIGH.

Most Americans have heard or read something about organ transplants, with 93% of a nationally representative sample of those age 18 years or over saying that they had. This level of awareness is relatively constant across all demographic variables except race, where 95% of white respondents have heard of organ transplants, but only 84% of black respondents.

MOST BELIEVE THAT SOMEONE HAS TO GIVE PERMISSION FOR THEIR OWN KIDNEY TO BE DONATED IN ORDER TO HAVE KIDNEYS AVAILABLE.

Among those aware of organ transplants, most (89%) believe, correctly, that somebody has to have given permission for their kidney to be donated after death in order for a kidney to be transplanted into someone who needs it.

MOST BELIEVE THAT A DOCTOR CANNOT ORDER KIDNEY REMOVAL.

88% also believe, correctly, that a doctor cannot give permission to remove the kidney of someone who has just died.

MANY FEWER BELIEVE THAT A RELATIVE OF SOMEONE WHO DIED CAN GIVE PERMISSION.

A smaller proportion, but still a substantial majority (64%) believe, correctly, that a relative of someone who has died can give permission to have that person's kidneys donated.

MORE PEOPLE ARE LIKELY TO GIVE PERMISSION FOR DONATION OF RELATIVE'S OR CHILD'S KIDNEYS RATHER THAN THEIR OWN KIDNEYS.

Almost three-quarters (72%) of those aware of organ transplants say they are very likely to give permission to have the kidneys of a loved one donated after that person's death, and half say they are very likely to donate their own child's kidneys in the event of accidental death. However, only 24% say they are likely to want their own kidneys donated after their own death.

THOSE WHO ARE MORE LIKELY TO WANT THEIR OWN KIDNEYS DONATED AFTER DEATH ARE MORE EDUCATED; WITH HIGHER INCOME; WHITE RATHER THAN BLACK.

Those who are most likely to want their own kidneys donated after their death are those who have completed more formal education and are in higher income brackets (two interactive variables). Blacks are much less likely than whites to want their own kidneys donated (10% vs 27%). These same demographic characteristics distinguish those more likely to give permission for the kidneys of a loved one or their own child to be donated.

WHEN ASKED TO RATE VARIOUS REASONS FOR NOT WANTING THEIR OWN KIDNEYS DONATED, THE MOST FREQUENT RESPONSE WAS "I NEVER REALLY THOUGHT ABOUT IT".

About one in five (20%) say that a very important reason for not wanting to have their kidneys donated after their death is that "I never really thought about it".

DISLIKE IDEA OF BEING CUT UP AFTER DEATH CITED AS "VERY IMPORTANT" BY ONE IN FIVE.

About the same proportion (20%) cite as a "very important" reason "I don't like the idea of somebody cutting me up after I die". No other reason was cited by that many respondents as being "very important".

FEW SAY THAT RELIGIOUS REASONS OR COMPLICATED PERMISSION PROCEDURES ARE VERY IMPORTANT.

Only 7% stated either of the following reasons "it is against my religion" or "it is complicated to give permission".

APPENDIX 4

CANADIAN GALLUP POLL - 1978 VS 1983

The questions were: "Would you, or would you not be willing to sign a form donating any of your vital organs for transplants, in the event of your death?" If YES, "Have you by any chance already signed such a form?"

	HAVE SIGNED ALREADY	HAVE NOT BUT WILLING	NOT WILLING	DON'T KNOW
NATIONAL				
1983	21%	38%	30%	11%
1978	12	41	36	11
REGION (1983)				
Atlantic	7	44	34	14
Quebec	17	44	30	10
Ontario	26	34	30	11
Prairies	23	37	30	10
British Columbia	27	37	24	11
AGE (1983)				
18 - 29 years	23	39	28	9
30 - 40 years	28	40	24	8
40 years and over	12	36	37	15

APPENDIX 5

CANADIAN NEUROSURGERY SOCIETY

Guidelines for the Determination of Brain Death

(Version of 18 February, 1985)

Preamble:

The development of techniques for the ventilatory and circulatory support of critically ill patients has created a need for new definitions of death. Although irreversible cessation of circulatory and respiratory functions acceptably defines death, irreversible cessation of brain function is also equivalent to death of the individual even though the heart continues to beat while the person is on a respirator. In 1968, following the publication of the "Harvard Criteria", the Canadian Medical Association provided quidelines for the diagnosis of brain death. In 1976, guidelines were published for the U.K. and in 1981 revised quidelines were approved by the American Neurological Association and the American Academy of Neurology. The following set of guidelines have been prepared by a subcommittee of the Canadian Congress of Neurological Sciences representing the Canadian Neurological Society, the Canadian Neurosurgical Society, the Association for Child Neurology and the Canadian Society of Clinical Neurophysiologists.

The determination of brain death is a clinical decision that must be made by an experienced physician in accordance with accepted medical standards. Thus, the guidelines described below are based on current medical information and experience. As knowledge advances, it can be anticipated that further revisions will become necessary. Because of the major consequences of the diagnosis of brain death, consultation with other physicians experienced in the relevant clinical examinations and diagnostic procedures is usually advisable.

Guidelines

The clinical diagnosis of brain death can be made when all of the following criteria have been satisfied:

1. An etiology has been established that is capable of causing brain death and potentially reversible conditions have been excluded (see Comment 2, below).

2. The patient is in deep coma and shows no response within the cranial nerve distribution to stimulation of any somatic area. No movements such as cerebral seizures, dyskinetic movements, decorticate or decerebrate posturing arising from the brain are present (see 1a, below).

3. The patient is apneic when taken off the respirator for an appropriate period of time (see 1b below).

4. Brainstem reflexes are absent (see 1c, below).

5. The conditions listed above persist when the patient is reassessed after a suitable interval (see 2, below).

Comments:

1. Cessation of Brain Function: The clinical absence of brain function is defined as: profound coma, apnea, and the absence of brainstem reflexes.

a) Coma. The patient should be observed for spontaneous behaviour and response to noxious stimuli. In particular, there should be no motor response within the cranial nerve distribution to stimuli applied to any body region. There should be no spontaneous or elicited movements (dyskinesias, decorticate or decerebrate posturing, epileptic seizures) arising from the brain. However, spinal reflexes may persist in the state of brain death.

b) Apnea was originally defined as lack of respirations when the patient was disconnected from the respirator for three minutes. This failed to take into consideration whether an adequate PaCO2 level was present to trigger respirations. The threshold for respiratory stimulation in comatose patients may be elevated to PaCO2 levels as high as 50-55 mm Hg and many patients on respirators have low PaCO2 levels which rise slowly (e.g. 2-3 mm Hg per minute) when the respirator is stopped. The technique of apneic oxygenation, described below, is a safe way of testing respiratory activity in such patients.

If blood gas determinations are available, the PaCO2 should be 40+/-5 mm Hg before testing for apnea begins. The respirator is then disconnected for 10 minutes while, to prevent hypoxemia, 100% O2 is delivered at 6 litres/minute through an endotracheal cannula. This should ensure an adequate rise in PaCO2 to serve as a respiratory stimulant. If blood gas determinations are not available, an adequate test of brainstem responsiveness to hypercarbia can be provided by ventilating the patient for 10 minutes with a 95% O2-5% CO2 mixture before the 10 minute period of apneix oxygenation. In patients with severe respiratory disease, it is advisable to obtain the opinion of a respiratory physician to determine the safety and validity of this test for apnea.

c) Brainstem Reflexes. The pupillary light, corneal vestibulo-ocular and pharyngeal reflexes must be absent. The pupils should be mid-position or larger and unreactive to light. Care should be taken that atropine or related drugs that could block the pupillary response to light have not been given to the patient. The vestibulo-ocular reflexes should be tested by doing caloric tests with up to 120 ml of ice-water while the head is 30° above the horizontal. Grimacing or any other motor response to pharyngeal or tracheal sunctioning is incompatible with a diagnosis of brain death.

2. Irreversibility: Cessation of brain function is determined to be irreversible when potentially reversible causes have been excluded and the changes are judged to be permanent. Drug intoxication (particularly barbiturates, sedatives, and hypnotics), treatable metabolic disorders, hypothermia (core temperature less than 32.2°C), shock, and peripheral nerve or muscle dysfunction due to disease or neurosmuscular blocking drugs must be excluded.

Re-evaluation is essential to ensure that the non-functioning state of the brain is persistent and to reduce the possibility of observer error. Depending on the etiology, the interval between such examinations may be as short as 2 hours or as long as 24 hours; observation for at least 24 hours is usally recommended to confirm brain death due to anoxia-ischemia (e.g. post-cardiac arrest). In situations where brain death is declared for purposes of organ transplantation, local regulations may stipulate specific intervals of reassessment.

Brain death has not been sufficiently well studied in neonates, infants and young children to determine how well the criteria apply to these age groups. One study suggests waiting a period of three days for children. Until further data are available, caution is recommended for the pediatric population.

Special Tests:

Brain death can be established reliably by clinical criteria alone. Special tests such as electroencephalograms, although not essential, can be used to support the clinical diagnosis of brain death. The electroencephalogram (EEG) assesses cerebral cortical funcion. Electrocerebral inactivity is confirmatory evidence of brain death if the full clinical criteria apply and established techniques are followed to ensure proper sampling of cortical activity. Visual, auditory, and somatosensory evoked responses may eventually prove to be useful but, at present, there are no standard guidelines for their use in assessing patients with suspected brain death.

The absence of intracranial perfusion, demonstrable by cerebral angiography or isotope brain scanning, is reliable evidence of brian death. The mean arterial pressure should be greater than 80 mm Hg when cerebral perfusion is assessed. Some clinical situations (e.g. inability to examine one or both eyes due to trauma, middle ear injuries, cranial neuropathies or severe pulmonary disease) may preclude the valid application of the listed clinical criteria. In these circumstances, the only reliable means of determining brain death is the absence of cerebral perfusion. If cerebral angiography or radionucleotide scanning is used to determine the absence of cerebral perfusion, the procedure should be performed by an appropriately qualified specialist.

ORGAN DONATION IN THE EIGHTIES:
A BLUEPRINT FOR SUCCESS

DONOR TRANSPORTATION SUBCOMMITTEE

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PROVINCE OF ONTARIO

TABLE OF CONTENTS

1.0 INTRODUCTION 137

2.0 OBJECTIVES 138

3.0 FACILITATION OF POTENTIAL ORGAN DONORS 139

4.0 DONOR/RECIPIENT TRANSPORTATION COSTS 139

5.0 ACCESSIBILITY TO PROVINCIAL ORGAN RETRIEVAL PROGRAM 141

6.0 CONCLUSIONS

6.1 FACILITATION OF POTENTIAL ORGAN DONORS 141

6.2 DONOR/RECIPIENT TRANSPORTATION COSTS 142

6.3 ACCESSIBILITY TO PROVINCIAL ORGAN RETRIEVAL PROGRAM 142

1.0 INTRODUCTION

In the organ donation process there are several steps in which transportation of either patients or organs is critically important. When head injury or acute trauma occurs, the patient is resuscitated and transported from the site of injury to the nearest hospital or, when applicable, the nearest trauma centre. If indicated, the patient is then transferred to a trauma or neurosurgical unit. Recent North American emergency medical experience has demonstrated that properly trained paramedics and an efficient rapid transport system often make the difference between life and death. The current Ontario Land and Air Ambulance system, with an accompanying paramedical or medical team, should provide a mechanism whereby more trauma victims are salvaged. As the Ontario paramedical program has only recently been initiated and no application to the Air Ambulance branch utilized as such, first hand experience is unavailable to date.

In some instances, due to the severity of the injury, irreversible damage occurs to the brain and such individuals are identified by the attending physicians to be suitable for organ donation. When this occurs in peripheral centres, transportation is required either to move the donor to a transplant centre or for the organ retrieval team to travel to the donor centre for organ removal. In the former case, following removal of the organs, the donor's body must be promptly returned to the funeral home for burial preparation. Specimens of donor spleen and lymph node tissue removed at the time of organ removal must be rushed to the tissue typing laboratory and, when no appropriate recipient is located in Ontario, specimens are dispatched by air express to other centres in Canada or the United States. Once a suitable recipient is located, the organs are then transported usually by land vehicle (e.g. O.P.P.) or by private or commercial aircraft to the recipient centre for transplantation.

When notified that an organ has been found, the recipient must travel immediately to the transplant centre usually by car but occasionally by airplane. These recipients are usually outpatients and, therefore, bear these transportation costs personally. In the case of living-related renal transplantation, the donor often lives a distance from the recipient and, thus, costs are incurred in travelling to the transplant centre for preliminary testing to determine compatibility and at a later date for the kidney removal operation.

2.0 OBJECTIVES

The objectives of this committee were threefold:

a) to assess the role of transportation factors in the organ donation process;

b) to determine if any barriers to organ donation exist as a result of deficiencies in these transportation factors; and

c) to make recommendations to correct any transportation-related barriers to the organ donation process.

3.0 FACILITATION OF POTENTIAL ORGAN DONORS

The subcommittee has reviewed the Ministry of Health's proposal for the establishment of regional trauma centres. There was a strong feeling that province-wide regional trauma centres represent an ideal entry into the health care system of potential donors. By providing this treatment facility to as many as possible, not only will there continue to be a decline in trauma-related mortality but inevitable treatment failures will be more readily available for organ donation. Because the success of regional trauma centres depends on excellent prior communication, triage treatment in the field as well as rapid transport of stabilized patients to the trauma centre, the subcommittee felt it important to emphasize that the Air Ambulance program continue to develop with the trauma centre system.

The subcommittee also felt that the Ministry of Health Air Ambulance central dispatch illustrates the ability of a dedicated solitary central facility to efficiently coordinate land and air transport facilities including commercial, private and government vehicles and aircraft. It was felt that the central dispatch should assist arrangements for the transportation of potential organ donors from centre to centre and for the transport of the retrieval teams to and from the donor centre.

4.0 DONOR AND RECIPIENT TRANSPORTATION COSTS

The subcommittee felt that costs involved in organ retrieval from a donor should be borne by the recipient's provincial medical plan. Such costs include the transportation of a donor from either within or out of Ontario to the recipient centre and the prompt return of the donor's body to the funeral home for preparation for burial. Other costs that can be incurred are:

a) the transportation of the retrieval team(s) to the donor centre for removal of the organs;
b) tissue typing expenses incurred out of the Province of Ontario to determine suitability of an out-of-province organ for an Ontario recipient; and
c) travel and other costs for out-of-province kidneys that are on perfusion that require accompaniement to the recipient centre by a perfusionist.

The subcommittee also felt that the issue of recipient transportation was important and suggests that OHIP consider recipient transportation for both work-up and transplantation to qualify as "urgent care". The current funding system for such transport is only activated when there is a hospital to hospital transfer which is often arranged for the covert, but sole, purpose of saving the patient money but which only leads to increased administrative work, expense, and delay.

Because 20 percent of current donors are living-related, it was felt that the transportation costs involved in testing such individuals for suitability as an organ donor as well as the costs incurred travelling to the transplant centre for donor nephrectomy should be borne by the recipient's provincial medical plan. In addition, the issue of lost income during the recuperative phase following kidney donation needs to be recognized. An appropriate mechanism for funding this cost was not readily identified. It was emphasized by the subcommittee that the expense involved in transportation of donors, recipients, retrieval teams and organs are minimal when compared to the costs of ongoing dialysis.

5.0 ACCESSIBILITY TO PROVINCIAL ORGAN RETRIEVAL PROGRAM

The subcommittee felt it was most important that a toll free Zenith number be established to provide immediate access by any concerned person or health professional to a province-wide organ retrieval and exchange program. This central 24-hour bureau would provide access to information for the public or health care workers, assistance with organ removal (i.e. mobilizing an organ retrieval team from a transplant centre) or initiate complete transplant arrangements if necessary.

Currently the M.O.R.E. program has a 1-800 24-hour line with an easily recalled number (387-LIFE). However, there is the broader issue of the establishment of a single organization easily identified as being responsible for organ retrieval and exchange.

6.0 DONOR TRANSPORTATION CONCLUSIONS

6.1 FACILITATION OF POTENTIAL ORGAN DONORS

1. Transport of potential organ donors should be facilitated by further development by Emergency Health Services Division of province-wide

regional trauma centres with a supporting province-wide 24-hour Air Ambulance Program.

2. The Ministry of Health Central Air Ambulance Dispatch Communications system should assist in donor transportation.

6.2 DONOR AND RECIPIENT TRANSPORTATION COSTS

Recipient's OHIP plan to cover the following costs:

1. recipient transportation costs (as insured "urgent care")
2. out-of-province donor transportation and other related costs.
3. the costs of returning the donor's body home for burial preparation including out-of-province and Ontario donors.
4. the transportation costs incurred by the organ retrieval team.

6.3 ACCESSIBILITY TO PROVINCIAL ORGAN RETRIEVAL PROGRAM

1. The development of a 24-hour provincial toll free telephone "hotline" should occur in order to access organ donation information or an organ retrieval team.

ORGAN DONATION IN THE EIGHTIES

A BLUEPRINT FOR SUCCESS

ORGAN RETRIEVAL AND DISTRIBUTION SUBCOMMITTEE

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TABLE OF CONTENTS

PAGE

1.0 INTRODUCTION.. 145

2.0 OBJECTIVES.. 145

3.0 INFORMATION BASE.. 146

4.0 ORGAN RETRIEVAL

4.1 Demography of Organ Retrieval.......................... 146

4.2 Institutional Considerations in Organ Retrieval......... 148

4.3 Professional Considerations in Organ Retrieval.......... 150

5.0 ORGAN DISTRIBUTION

5.1 Technical Considerations in Organ Distribution........... 153

5.2 Immunological Considerations in Organ Distribution....... 161

5.3 Organizational Considerations in Organ Distribution...... 165

6.0 ECONOMICS AND EFFICIENCY OF ORGAN RETRIEVAL

6.1 Economics.. 166

6.2 Efficiency.. 168

7.0 OPTIMIZATION OF ORGAN RETRIEVAL AND DISTRIBUTION: 170
DEVELOPMENT OF AN INTEGRATED PROVINCIAL AND NATIONAL TRANSPLANT PROGRAM

8.0 DISCUSSION AND CONCLUSIONS..................................

8.1 Institutional Considerations in Organ Retrieval 174
8.2 Professional Considerations in Organ Retrieval 174
8.3 Technical Considerations in Organ Distribution 175
8.4 Immunological Considerations in Organ Distribution 175
8.5 Organizational Considerations in Organ Distribution 176
8.6 Economics and Efficiency of Organ Retrieval 176

1.0 INTRODUCTION

Maintenance of the potential non-living donor during the critical time between donor identification and organ transplantation requires the commitment and active collaboration of multiple health care professionals. The provision of appropriate donor support, definition of the organs required, and selection of the surgical teams involved must be executed quickly and with a minimum of parochial and institutional concerns. Following removal, a finite interval is available for distribution of the organ to the appropriate recipient. The optimal form of organ preservation during this time, and the criteria for recipient selection have not been uniformly accepted. These factors influence considerably decision making in organ distribution, impacting both on the cost/effectiveness of organ retrieval and upon equitable distribution of the organs recovered.

The mandate of this committee is to examine the factors involved in retrieval and distribution of organs from the non-living donor, and to develop a concensus regarding optimal practice with reference both to patient benefit and financial implications.

2.0 OBJECTIVES

The objectives defined by this committee were three-fold:

a) To examine steps involved in the retrieval and distribution of organs from the non-living donor for the purposes of transplantation and to define those disincentives and barriers which impede this process.

b) To examine the economics, efficiency and cost effectiveness of organ retrieval and distribution in Ontario by comparison with other established programs.

c) To determine the changes in current practice within the province required to optimize recovery and promote more efficient use of organs for transplantation.

3.0 INFORMATION BASE

The information base employed to achieve these objectives was compiled from five major sources:

a) published scientific literature,
b) publications of the Ontario Ministry of Health,
c) the Centre for Transplant Studies, University Hospital, London,
d) the Metro Organ Retrieval and Exchange Program, and
e) surveys performed of transplantation programs within the Province of Ontario, Canada, and the United States.

This information was used to define:

a) The demography of organ retrieval in Ontario.
b) The institutional and professional barriers to organ retrieval.
c) The demography of organ distribution in Ontario.
d) The technical and organization barriers to organ distribution, and
e) The comparative economics of organ retrieval and distribution.

4.0 ORGAN RETRIEVAL

4.1 Demography of Organ Retrieval

Kidney transplantation within the province of Ontario is performed at nine designated University centres. The geographical location of these institutions, coupled with the natural referral patterns based on clinical patient care, define the five transplantation regions whose designated centres are shown in Table 1. Provision of health care within each of these regions is ensured by institutions divided into primary, secondary and tertiary centres on the basis of size, facilities, and referral base. Primary care institutions, small hospitals of less than 100 beds, subserve local community needs; secondary care institutions function as intermediate referral centres, providing more extensive facilities and encompassing special care units; tertiary health care institutions, situated in the larger cities, are affiliated with medical schools, provide comprehensive medical care and function as regional referral centres.

TABLE 1: NUMBER OF CADAVERIC KIDNEY DONORS IN ONTARIO (1981 - 1983)[1]

MAJOR REGIONS	TERTIARY HOSPITALS	SECONDARY HOSPITALS	PRIMARY HOSPITALS	TOTAL DONORS	REFERRED AS DONORS
OTTAWA	35	0	0	35	0
KINGSTON	11	0	0	11	0
TORONTO (1)	106	13	0	119	12
HAMILTON	33	13	0	46	0
LONDON (2)	74	10	0	84	7

(1) Includes Northwestern Ontario
(2) Includes Northeastern Ontario

The retrieval of organs from non-living donors for the purposes of transplantation has developed within the context of these defined regional transplantation programs. The number of such donors in the province of Ontario within the last 3 years (1981-1983, inclusive) is shown in Table 1 distributed by region and source.

Approximately 90 kidney donors per annum proceed to nephrectomy. The overwhelming majority of these operations (93%) occurred in each region within tertiary hospitals. Between 0-10% (mean: 7%) of such donors were referred expressly for purposes of organ donation following declaration of brain death in a peripheral primary or secondary health care institution. In the remaining cases, the donor was identified and death declared within the tertiary hospital.

Organ recovery was uncommon in secondary care institutions within the province. A total of only 19 donors were identified and proceeded to nephrectomy in these hospitals during the three years surveyed, reflecting 7% of total organ donors during this time. No donor organs were obtained from primary care institutions within the province during the period surveyed.

4.2 Institutional Considerations in Organ Retrieval

Institutional barriers to organ retrieval may be broadly divided into two categories, those pertaining to facilities available, and those related to financial concerns.

a) Facilities

Identification of the potential organ donor is within the scope of almost all hospitals which provide general medical care, irrespective of size and sophistication. However, maintenance of the non-living donor and subsequent organ retrieval require extensive medical facilities to permit appropriate respiratory and cardiovascular care, and medical and surgical expertise commensurate with the support of the critically ill patient. The complexity of these requirements is such that primary health care institutions, not equipped with special care unit beds, are not reasonably able to provide this service (Table 2).

TABLE 2: HOSPITAL FACILITIES IN ONTARIO (1983)[2]

MAJOR	TERTIARY		SECONDARY		PRIMARY	
REGIONS	NUMBER	SCU BEDS	NUMBER	SCU BEDS	NUMBER	SCU BEDS
OTTAWA	3	85	13	68	10	0
KINGSTON	2	34	4	24	3	0
TORONTO (1)	7	132	47	495	25	0
HAMILTON	4	131	11	108	2	0
LONDON (2)	3	69	39	354	26	0

(1) Includes Northwestern Ontario

(2) Includes Northeastern Ontario

The requisite facilities are readily available in major secondary care institutions and tertiary care institutions, which will consequently become a focus for referral and support of the potential donor. Such referral creates an increasing load on life support service within these institutions and will ultimately create serious competition for essential services.

b) Financial Issues

A comprehensive analysis of the costs incurred by the institution in donor support and organ retrieval is shown in Table 3. This analysis was performed using a precise cost accounting system employed at University Hospital, London, which was devised following consultation with functionally comparable non-profit teaching hospitals throughout North America. This cost accounting system reflects actual expenditure for patient care excluding opportunity costs but encompassing materials and salaries incurred in providing these services. Costs for donor support have been defined from the time of notification of the transplant team until the time of organ removal. The mean cost of donor support is $4,226 (Cdn), with a range of $2,564 to $5,868, reflecting the duration of support and complexity of investigation and patient care. The mean cost per kidney is $2,414. It is clear from this analysis that the cost per organ is dramatically reduced when multiple organs are removed from the same donor.

The potential organ donor thus represents a considerable non-reimbursable expense to the hospital involved. Such expenditure will increase with the increasing concentration of organ donors in those centres possessing facilities and personnel capable of donor support. No mechanism for reimbursement of these institutions is currently in place.

TABLE 3: INSTITUTIONAL COSTS OF ORGAN RETRIEVAL[3]
(EXCLUDING OPPORTUNITY COSTS)

NUMBER OF DONORS	AVERAGE COST PER DONOR	COST RANGE	COST PER ORGAN	COST PER KIDNEY
8 (1)	$ 4226	$ 2564 - 5868	$ 2414	$ 2414 (2)
7 (3)	$ 5250	$ 3795 - 6788	$ 1313	$ 1500 (2)

(1) Only kidneys were retrieved from these donors

(2) Assume that 1.75 kidneys are transplanted per donor.

(3) Kidneys and other organs were retrieved from these donors. An average of 4 (3 - 5) organs were retrieved from these donors. These organs included eyes, heart, liver, pancreas, skin, extremity bones.

(4) These costs include donor support in the Intensive Care Unit; diagnostic tests to establish brain death and donor suitability and Operating Room time for retrieval of organs(s)

4.3 Professional Considerations in Organ Retrieval

Three professional barriers to organ retrieval were addressed: clinical expertise, professional remuneration, and constraints of clinical practice.

a) Clinical Expertise:

Optimal support of the potential organ donor and recovery of vital organs requires a critical level of expertise gained by both education and experience and sustained by continuing activity in this role. While anxious to promote organ retrieval to the fullest extent, many physicians not regularly engaged in this process recognize that they do not possess the requisite expertise, and require assistance in donor support.

b) Professional Remuneration:
The medical personnel involved in the care of the non-living donor and professional remuneration are indicated in Table 4 by subspecialty. The timing of donor notification and surgical intervention has been identified based on a retrospective survey performed at University Hospital, London. Approximately 50% of donor notifications occur in the evening or at night, while 60-100% of donor nephrectomies occur in evening, at night, on weekends or statutory holidays. The allowable premium for consultation or provision of care within these hours has been factored and summated.

TABLE 4: PROFESSIONAL COSTS OF KIDNEY RETRIEVAL[4]
BASED ON CURRENT OHIP SCHEDULE (1984)

SPECIALIST	FEES PER DONOR (1)	FEES PER KIDNEY (2)
Nephrologist	$ 271.44	$ 155.11
Intensivist	170.40	97.37
Internist	98.59	56.34
Neurosurgeon	79.09	45.19
Urologist	145.51	263.74
Surgical Assistant	145.51	83.15
Anesthesiologist	211.82	121.04
TOTAL	$ 1,438.40	$ 821.94

(1) Assume only kidneys are retrieved from donor
(2) Assume 1.75 kidneys retrieved are transplanted per donor.

To determine whether professional remuneration was considered inadequate, and a disincentive to donor support and organ retrieval, the medical personnel involved in this process at 7 transplant centres within the province were surveyed. Lack of adequate remuneration was not considered by any of the individuals surveyed to be a barrier to organ retrieval.

Two related concerns were voiced, however, by the subjects interviewed. Firstly, the assessment of the potential organ donor occupied considerable time, both in definition of brain stem function and in discussing organ transplantation with the next of kin. This is frequently performed by the attending physician, either in a peripheral hospital or in a tertiary centre. No mechanism of reimbursement for this important clinical function currently exists within the schedule of benefits. Secondly, depending upon the clinical practice of the institution, the responsibility for clinical support of the donor rests entirely with the neurosurgeon or nephrologist involved. In many cases, these subspecialists considered that the remuneration did not reflect adequate recompense for the considerable time involved in donor care.

c) Constraints of Clinical Practice:

This was identified as the single most important concern expressed by physicians in relation to support of the non-living donor. It is clear that despite the desire to promote organ retrieval, the necessity of devoting a large amount of time to such a donor at the expense of one's own practice is perceived as a major disincentive to donor notification and support by those physicians not intimately connected with organ transplantation.

5.0 ORGAN DISTRIBUTION

The exchange of organs between transplant centres is performed to increase the efficiency of transplantation by eliminating organ wastage and promoting graft survival. Three considerations which impact directly upon this process were addressed.

5.1 Technical Considerations in Organ Distribution

a) Organ Preservation

Following nephrectomy, the kidney is core-cooled to decrease the rate of cellular metabolism, and may then be perserved for a defined peiod of time prior to transplantation. Two methods of preservation are currently employed within the province of Ontario as shown in Table 5:

1) cold storage, performed in an ice-cooled container, is simple and cost effective;

2) pulsatile machine perfusion is more complex, expensive and requires continual technical supervision, but has been suggested to permit better graft function and survival.

Selection of the superior modality has important implications for both the cost and efficiency or organ distribution.

TABLE 5: KIDNEY PRESERVATION IN CANADA (1981 - 1983)[1,5]

REGION	NUMBER OF KIDNEYS	PERCENTAGE COLD STORAGE	PERCENT MACHINE PERFUSED
Ontario	603	27.0	73.0
Canada (excluding Ontario)	354	59.3	40.7
Canada	957	39.4	60.6

The efficacy of cold storage was compared to that of pulsatile machine perfusion using the endpoint of graft survival by means of:

1) crosstabulation and statistical reanlaysis of data currently reported in the literature,

2) analysis of information derived prospectively within the Canadian Multicentre Transplant Study and

3) information derived from randomized controlled studies of organ preservation.

The results of the historical analysis is presented in Table 6. The data base employed was created from an extensive literature review encompassing 36,005 patients. Cross tabulation of survival by method of preservation was performed with a chi-squared test of statistical significance. Control for both warm and cold ischemic time was also performed by cross tabulation. A multiple classification analysis was performed to assess the influence of other variables. Graft survival at one year in patients receiving cold stored kidneys was found to be significantly superior overall to those receiving machine perfused organs (P =0.01), this influence being independent of warm ischemic time, and evident up to 48 hours of storage.

TABLE 6: EFFECT OF KIDNEY PRESERVATION METHOD ON GRAFT SURVIVAL AT ONE YEAR

A STATISTICAL ANALYSIS OF THE LAST TEN YEARS WORLD EXPERIENCE

(i) OVERALL

	NUMBER	% SURVIVAL (1)
COLD STORAGE	8,666	56.9
MACHINE PERFUSION	13,752	50.2

1. $p = 0.01$

(ii) INFLUENCE OF WARM ISCHEMIC TIME

	< 30 MINUTES		≥ 30 MINUTES	
	NUMBER	% SURVIVAL (2)	NUMBER	% SURVIVAL (3)
COLD STORAGE	5702	57.6	263	62.0
MACHINE PERFUSION	6743	50.2	206	39.3

2. $p = 0.001$
3. $p = 0.001$

(iii) INFLUENCE OF COLD ISCHEMIC TIME

	< 24 HOURS		24 - 48 HOURS	
	NUMBER	% SURVIVAL (4)	NUMBER	% SURVIVAL (5)
COLD STORAGE	5002	57.3	376	54.3
MACHINE PERFUSION	3635	47.5	2823	49.5

4. $p = 0.001$
5. N/S

NOTE: Statistical analysis of world literature in the past decade. A complete reference list is available upon request.

The Canadian Multicentre Transplant Study Group (CMTSG), established in 1980, encompasses 17 participating transplant centres throughout Canada. In excess of 800 patients have now been transplanted within this group, according to uniform protocols of management and immunosuppression. Current analysis of actuarial graft survival of 428 graft recipients from non-living donors by method of organ preservation is shown in Table 7. Analysis was performed on data stratified for donor source (living donor vs non-living donor), and transplant number (1st transplant vs multiple transplant). Overall actuarial one year graft survival was independent of the mode of organ preservation in patients receiving either 1st or subsequent kidney grafts, although preliminary analysis suggested an adverse interaction between prolonged machine perfusion and cyclosporine immunosuppression upon ultimate graft survival.

TABLE 7: EFFECT OF PRESERVATION METHOD ON GRAFT SURVIVAL AT ONE YEAR
A STATISTICAL ANALYSIS OF THE CTMSG STUDY[6]

	Number	1-12hr	12-24hr	24-36hr	36+hr	Overall
a) First Graft						
Cold Storage	229	72%	82%	72%	50%	75%
Machine Perfusion	128	85%	79%	73%	61%	74%
b) Multiple Graft						
Cold Storage	54	77%	50%	43%	--	59%
Machine Perfusion	21	100%	64%	60%	50%	58%

Prospective randomized studies comparing cold storage and machine perfusion have been performed both in Australia and Canada. The results are presented in Table 8. No effect of preservation method was observed in the former study, although patient and graft survival were significantly lower in patients receiving cold stored kidneys in the Canadian trial.

TABLE 8: GRAFT SURVIVAL AT ONE YEAR ACCORDING TO METHOD OF KIDNEY PRESERVATION: PROSPECTIVE RANDOMIZED STUDIES

	Australian Study[7]		Canadian Study[8]	
	#	Survival	#	Survival
COLD STORAGE	101	55%(1)	90	70%(1)
MACHINE PERFUSION	80	49%	91	73%

(1) p = ns

The capital and operating costs for cold storage and machine perfusion are shown in Tables 9 and 10 respectively. Cold storage represents a substantial saving in both capital costs ($50 vs $25,000) and operating costs ($113 vs $808), if efficacy of storage as measured by graft survival and function is similar for both techniques.

TABLE 9: PRESERVATION OF CADAVER KIDNEYS FOR TRANSPLANT[9]

CAPITAL EXPENDITURES

COLD STORAGE		MACHINE PERFUSION	
1 cooler for storage of kidneys from nephrectomy to transplant	$45.00	Machine for pulsatile perfusion (*)	$25,000
1 styrofoam box for transportation of kidney	$ 5.00		
TOTAL	$50.00	TOTAL	$25,000

* The capital cost for perfusion machines depends on the make of machine and the number of machines required. At least one console model and one portable model is required in each centre. Busier centres will require more than one of each type. For example:

Waters Kidney Perfusion Machine	- Console	$ 18,000
	- Portable	$ 12,000
Gambro Kidney Perfusion Machine	- Console	$ 12,000
	- Portable	$ 8,000

TABLE 10: PRESERVATION OF CADAVER KIDNEYS FOR TRANSPLANT SUMMARY OF EXPENDITURES FOR ONE KIDNEY [9]

(i) KIDNEY IS TRANSPLANTED LOCALLY

	COLD STORAGE	MACHINE PERFUSION
Perfusionist salary	$ 82.13	$ 123.75
Materials and Supplies	$ 31.23	$ 684.98
TOTAL	$ 113.36	$ 808.73

(ii) KIDNEY IS TRANSPLANTED IN ANOTHER CENTRE

	COLD STORAGE	MACHINE PERFUSION
Pefusionist salary	$ 93.38	$ 225.00
Materials and Supplies	$ 31.23	$ 684.98
TOTAL (*)	$ 124.61	$ 909.98

* Actual transportation costs vary.

COLD STORAGE:

$0.00 to $75.00 depending on whether the kidney is transported by the O.P.P. or sent by Commercial Air Carrier.

MACHINE PERFUSION:

It is impossible to calculate an average cost per kidney. If the kidney is transported by private car (with the transplant co-ordinator) then mileage is charged @ $0.20 per kilometre. If the kidney is transported by commercial airplane, then two tickets must be purchased: one for the co-ordinator and one for the machine/kidney. Depending on the distance and the scheduled flights, it may be necessary to provide accommodation and meals for the co-ordinator. An estimate of this expense is $100.00 to $1,500.00.

b) Organ Transport:

Four methods are currently employed to transport kidneys intraprovincially and interprovincially, and are outlined in detail with their relative advantages and disadvantages in Table 11.

1. Air Canada - Expedair Service is fast and inexpensive ($50-$75) but is limited by the flight schedule. In addition, transport of organs requiring pulsatile perfusion necessitates an accompanying technologist thus increasing the cost considerably.

2. The use of a private car by the Transplant Coordinator minimizes the cost, and also permits transport of perfused organs if appropriate equipment is available. It is demanding on personnel time, however, and with this consideration may be less cost effective.

3. The use of a dedicated vehicle is also limited by considerations of capital cost and maintenance, as well as the additional expense of technician time.

4. Approximately 70% of organs distributed within the province are currently transported, with great reliability, by the Ontario Provincial Police as a community service provided by this force. Although this is provided free of charge, the costs incurred are probably comparable to those in the use of a private vehicle. This method of distribution is extremely efficient, but is limited to cold stored kidneys.

TABLE 11: METHODS OF ORGAN TRANSPORT BETWEEN TRANSPLANT CENTRES 9

Service	Disadvantages	Suitable for Organs Cold Stored	 Machine Perfused
Air Canada - Expedair	Limited by flight schedule	yes	yes, when accompanied by technologist
Private vehicle	Limited by personnel time	yes	yes
Dedicated vehicle	Limited by personnel time	yes	yes
Ontario Provincial Police	--	yes	no
Courier	Appropriate licensing required	yes	no

A final potential mode for transportation is the use of commercial courier, although appropriate licensing arrangements must be made with the Ontario Highway Transport Board to permit transport of human organs. Costs are low and the service is readily available but is limited to cold stored kidneys.

5.2 Immunological Considerations in Organ Distribution

Two considerations were addressed: transplantation in the presensitized patient, and histocompatibility matching.

a) The Presensitized Patient:

Patients currently awaiting urgent transplantation may be divided into those requiring transplantation because of clinical need, and those for whom the selection of a suitable donor is difficult because of presensitization. There is uniform agreement that organ sharing to achieve transplantation for the former group is both important and valuable. However, review of previous information and analysis of recent data calls into question the value of organ sharing expressly to permit transplantation in highly sensitized patients. This data is presented in Tables 12 and 13. Analysis of results from 550 patients within the Canadian Transplant Study Group indicates that humoral sensitization is a serious potential prognostic factor in patients awaiting transplantation. In those patients awaiting a second or subsequent transplant who have antibodies exceeding 75%, graft survival at one year is 29%.

TABLE 12: INFLUENCE OF RECIPIENT VARIABLES ON GRAFT SURVIVAL: CYTOTOXIC ANTIBODY [10]

1. 1st Cadaver Graft	1 Yr. Graft Survival	
% Pra	Current Ab	Highest Ab
0 - 9	77[1] (232)[2]	79(176)
10 - 49	75(65)	76(94)
50 - 74	74(23)	67(34)
90 - 100	25(4)	54(13)
75 - 100	50(10)	59 (2)
P	.0002[3]	.020

[1] Acturial Survival

[2] n

[3] Breslow

TABLE 13: INFLUENCE OF RECIPIENT ON GRAFT SURVIVAL: CYTOTOXIC ANTIBODY [10]

2. 2nd Cadaver Graft

% Pra	1 Yr. Graft Survival Current Ab	 Highest Ab
0 - 9	61(33)[2]	86(7)
10 - 49	64(20)	58(26)
50 - 74	75(12)	83(19)
75 - 100	29(7)	35(20)
90 - 100	0(4)	33(12)
p =	.009[3]	.036

---

[1] Actuarial Survival [2] n [3] Breslow

TABLE 14: INFLUENCE OF ANTIBODIES ON GRAFT SURVIVAL: UNIVERSITY OF PITTSBURGH[11]

% Pra	2nd Yr. Graft Survival 1st Graft	 1+ Graft
0 - 30	75%	64%
31 - 99	55%	41%
p =	.01	.05

b) Histocompatibility Match:

The success of transplantation performed between related individuals is determined by the proximity of the histocompatibility match. That an improvement in graft survival following transplantation from non-living donors may also be obtained by matching for currently defined antigens within the HLA system has been consistently advocated by certain European and North American centres, although this has been difficult to demonstrate in single centre studies performed on this continent. To examine the validity of this concept, a pooled evaluation was performed retrospectively by crosstabulation and statistical reanalysis of data currently reported in literature. This analysis indicated a significant improvement in graft survival with compatibility at the AB, and DR locus (Table 15) which was evident in all geographic areas studied (North American, Europe and Australia).

TABLE 15: GRAFT SURVIVAL AT ONE YEAR ACCORDING TO HISTOCOMPATIBILITY MATCH: DERIVED FROM WORLD LITERATURE

MATCH	NUMBER	GRAFT SURVIVAL
AB Antigens		
2	1111	65%[1]
2	617	54%
DR Antigens		
2	84	85%[2]
1	343	71%
0	250	70%

[1] $p = 0.001$ [2] $p = 0.01$

NOTE: Statistical analysis of world literature in the past decade. A complete reference list is available upon request.

Analysis of data derived from the Canadian Multicentre Transplant Study Group trials indicated a similar trend, with a 15% increase in graft survival in patients receiving kidneys matched at the B or DR locus, or where no detectable mismatch existed at these loci (Table 16). Within these studies, transplantation was not performed on the basis of histocompatibility matching, thus accounting for the small number of highly matched organs.

TABLE 16: GRAFT SURVIVAL AT ONE YEAR ACCORDING TO HISTOCOMPATIBILITY MATCH: DERIVED FROM CMTSG STUDY [10]

MATCH	NUMBER	GRAFT SURVIVAL
B Antigens		
2	9	89%
1	142	77%
0	208	73%
DR Antigens		
2	19	89%
1	125	73%
0	175	73%

5.3 Organizational Considerations in Organ Distribution

a) Organ Sharing:

Within the province of Ontario, organ sharing between centres and regions has been performed by rota, the transplant centre which procures two kidneys retaining one for transplantation on site and contributing the second to a provincial pool for distribution to the next awaiting centre on a rotational basis. This system has certain merits, providing organs for patients in urgent need and permitting maximum utilization of a limited resource such that approximately 95% of organs recovered are ultimately transplanted. There are two major disadvantages to this system, however: firstly, organ distribution is not based upon parameters influencing graft survival, but is simply a redistribution of available kidneys. There is thus no improvement in efficiency of utilization of this resource, as measured by an increase in successful transplantation. Secondly, and of overriding concern, this system of distribution leads to marked operational inequities, such that certain regions become net organ producers while others are net consumers of organs. There is thus within the current system a potential disincentive for active organ retrieval.

b) Program Funding:

Organ retrieval within the province of Ontario is ensured by the five regional organ retrieval programs based in Ottawa, Kingston, Hamilton, Toronto and London. Direct funding for program support encompassing personnel and equipment costs is currently provided only to the Multiple Organ Retrieval and Exchange Program serving metropolitan Toronto and the surrounding region. In other centres, limited funding is derived from within the global budget of the respective institutions. Such disproportionate reimbursement seriously limits effective program development, and consequently impacts upon efficiency of organ retrieval.

6.0 ECONOMICS AND EFFICIENCY OF ORGAN RETRIEVAL

6.1 Economics

The economics of organ retrieval, encompassing the costs of donor support, preservation, transportation, tissue typing, crossmatching and professional fees, were examined for the province of Ontario, and are shown in Table 17. The global cost per organ transplanted is dependent upon the number of organs retrieved per donor, the type of preservation and distance of transport. Utilizing this information, maximum and minimum projected costs per organ transplanted may be calculated and are shown below:

Minimum cost per organ: $3,084

Maximum cost per organ: $5,194

TABLE 17: SUMMARY OF THE COSTS OF RETRIEVING AND DISTRIBUTING ONE CADAVERIC KIDNEY [3,4,9]

	DOLLARS PER KIDNEY (1)	
	MIN. COST	MAX. COST
DONOR SUPPORT	1500.00 (2)	2414.00 (3)
PROFESSIONAL FEES (3)	822.00	822.00
PRESERVATION	113.00 (4)	809.00 (5)
TRANSPORTATION	0.00-75.00 (4)	100.00-1500.00 (5)
TISSUE TYPING	106.00	106.00
CROSS-MATCHING	543.00	543.00
TOTAL	3084	5194

(1) Assume that 1.75 kidneys are transplanted per donor
(2) Several organs including kidneys are retrieved from the donor
(3) Only kidneys are retrieved from the donor
(4) The kidneys are preserved by cold storage
(5) The kidneys are preserved by machine perfusion

Eleven major Canadian transplant centres outside the province of Ontario were surveyed to determine costs involved in organ transplantation in other provinces. Six of the centres surveyed responded (54.5%). Three were unable to provide an estimate of costs associated with kidney retrieval and distribution. The other three centres estimated their expenses for kidney retrieval and distribution at $1,400, $2,000 and $3,000 for an average cost per kidney of $2,133. No further breakdown of expenses was provided, and the accuracy of these assessments can thus not be established at this time.

Twenty three major American transplant programs were also surveyed, of whom twelve (52.2%) responded. Two programs excluded crossmatching costs and one program excluded transportation costs (noting this to be a variable expense) in estimating their costs associated with kidney retrieval and distribution. The cost per retrieval and distribution of one cadaver kidney in the U.S.A. as reported by this survey averaged $8,153 (U.S.) ($10,436 Cdn) and ranged from $1,737.50 to $13,300 (U.S.).

6.2 Efficiency

The efficiency of organ procurement within the province of Ontario was analysed for a three year period during the years 1981 to 1983 inclusive. The results of this survey are shown in Table 18. A mean of 26.7 kidneys were obtained per million population with a range of 24.6 to 28.0. Kidney transplantation was performed at a comparable rate of 24.8 per million population with a range of 22.9 to 25.8. 92.8% of kidneys which were obtained from non-living donors were transplanted.

TABLE 18: ANNUAL RETRIEVAL AND DISTRIBUTION OF CADAVER KIDNEYS IN ONTARIO (1981 - 1983) [5]

	MEAN	RANGE
Kidney transplants per million population	24.8	22.9 - 25.8
Kidney nephrectomies million population	26.7	24.6 - 28.0
% Kidneys nephrectomized but NOT transplanted	7.2	6.8 - 7.6

The annual retrieval and distribution of cadaver kidneys in other Canadian provinces excluding Ontario is shown in Table 19. During the same three year period, a mean of 15.5 kidneys were obtained from non-living donors per million population with a range of 7.7 to 25.0. Kidney transplantation was performed at a rate of 16.1 per million population. 83% of kidneys removed from non-living donors were transplanted at that centre, and only 9.7% of organs distributed for transplantation in another centre. The proportion of kidneys from non-living donors which were transplanted was 92.7%, comparable to that in Ontario.

TABLE 19: ANNUAL RETRIEVAL AND DISTRIBUTION OF CADAVER KIDNEYS IN CANADA EXCLUDING ONTARIO (1981-1983) [5]

	MEAN	RANGE
Kidney transplants per million population	16.1	7.1 - 25.0
Kidney nephrectomies million population	15.5	7.7 - 25.0
% Kidneys nephrectomized and transplanted in own centre	83.0	60.0 - 100.0
% Kidneys nephrectomized and transplanted in other centres	9.7	0.0 - 43.5
% Kidneys nephrectomized but NOT transplanted	7.3	0.0 - 20.0
% Kidneys transplanted and nephrectomized in own centre	81.1	54.5 - 100.0
% Kidneys transplanted but nephrectomized in other centres	18.9	0.0 - 45.5

For purposes of comparison, the annual retrieval and distribution of cadaver kidneys in the American programs surveyed is reported in Table 20. A mean of 44.6 kidneys per million population were recovered during this three year period. Kidney transplantation was performed with a mean incidence of 38.7 per million population, and 85.2% of kidneys recovered from non-living donors were transplanted.

TABLE 20: ANNUAL RETRIEVAL AND DISTRIBUTION OF CADAVER KIDNEYS IN THE U.S.A. (1981 - 1983) [5]

	MEAN	RANGE
Kidney transplants per million population	38.7	11.1 - 122.0
Kidney nephrectomies per million population	44.6	20.1 - 100.0
% Kidneys nephrectomized but NOT transplanted	14.8	0.0 - 37.5

7.0 OPTIMIZATION OF ORGAN RETRIEVAL AND DISTRIBUTION: DEVELOPMENT OF AN INTEGRATED PROVINCIAL AND NATIONAL TRANSPLANT PROGRAM

Organ retrieval is most effectively achieved on a regional basis, where there is optimal opportunity for continuing and bidirectional interaction between the medical personnel at peripheral health care institutions throughout the region and those in the designated regional transplant centres. In contrast, the potential importance of tissue matching in improving graft survival argues strongly for an interactive organ exchange program at both a provincial and national level.

A model is proposed in Figure 1 which would permit these objectives. Within each of the defined regions, the regional transplant centre would have both the responsibility and obligation for interaction with participating health care institutions in order to·

1) provide continuing education regarding organ transplantation,

2) develop and maintain collaboration at that institution by creation of a liaison committee,

3) ensure that all procedures and policies are approved and operative to maximize organ retrieval, and

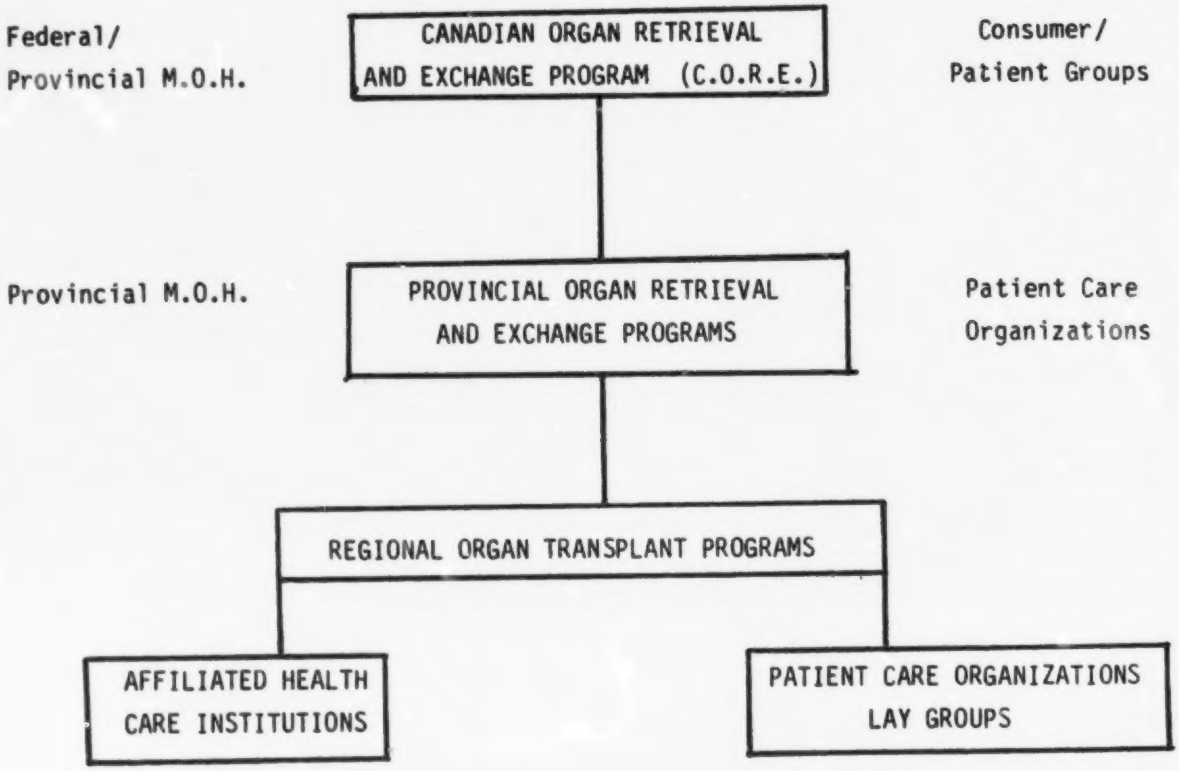
4) establish a donor support team consisting of the necessary medical, surgical and support staff so that donor maintenance and organ retrieval can be effected quickly and efficiently within the region as required.

Facilities for complete tissue typing would be established at each centre, permitting rapid typing of each donor and matching with the most suitable recipient on a computerized provincial waiting list. Distribution of the kidney to the transplanting centre would then be performed by the most cost effective and efficient method. Coordination of policy and procedures between the centres would be ensured by a provincial committee composed of representatives from each of the regional transplant centres. A chairman would be appointed from within this committee with a term of two years to supervise organization and function. This committee would be responsible for quality control in the areas of public and professional education, techniques of organ retrieval and storage, and adequacy and availability of tissue typing throughout the province, and would function to ensure uniformity wherever possible to facilitate interaction and reduce costs. Further, this committee would maintain the incentives for organ retrieval by ensuring organ distribution in proportion to regional contribution.

On a national scale, the provincial body would interact directly with corresponding organizations in the other provinces via a national committee composed of representatives from provincial organ retrieval programs. Organ sharing would thus be facilitated on a national basis, increasing the pool of potential recipients and improving the possibility of histocompatibility matching. In addition to their operational responsibilities, these committees at both the provincial and national level would serve an important function in defining areas of research and coordinating research activities in these fields.

FIGURE 1

STRUCTURE FOR AN INTEGRATED NATIONAL ORGAN RETRIEVAL AND EXCHANGE PROGRAM


Federal/
Provincial M.O.H.
CANADIAN ORGAN RETRIEVAL AND EXCHANGE PROGRAM (C.O.R.E.)
Consumer/
Patient Groups
Provincial M.O.H.
PROVINCIAL ORGAN RETRIEVAL AND EXCHANGE PROGRAMS
Patient Care
Organizations
REGIONAL ORGAN TRANSPLANT PROGRAMS
AFFILIATED HEALTH CARE INSTITUTIONS
PATIENT CARE ORGANIZATIONS
LAY GROUPS

8.0 DISCUSSIONS AND CONCLUSIONS

8.1 INSTITUIONAL CONSIDERATIONS IN ORGAN RETRIEVAL

Based on both demographic and institutional data, it is evident that a uniform policy mandating the establishment of facilities capable of donor support and organ retrieval in all provincial health care institutions is undesirable in terms of cost effectiveness. Further, it is recognized that the donor yield from certain instituions is less than would be expected in terms of their current clinical practice and facilities. Therefore, it is suggested that:

1. A uniform educational policy regarding multi-organ retrieval should be adopted throughout the province and actively propagated by each regional centre.
2. The secondary and tertiary health care centres currently capable of donor support and organ retrieval should be clearly identified and donor support and organ retrieval be mandated as a responsibility in clinical care.
3. Mechanisms for instituional reimbursement for maintenance of the organ donor should be negotiated through the life support program.

8.2 PROFESSIONAL CONSIDERATIONS IN ORGAN RETRIEVAL

Although their magnitude cannot be assessed objectively at the present time, the professional concerns identified are a clear disincentive to organ retrieval within the present health care system. In addition, it is anticipated that these difficulties will become more acute as the number of potential organ donors increases, presenting a distinct barrier to effective organ retrieval. The proposals of the Committee to eliminate the professional difficulties and disincentives are as follows:

(1) That initial assessment of the potential organ donor, encompassing evaluation of neurological status and introduction of the concepts of organ donation to the next of kin, be considered as a distinct and important medical service, and that appropriate recognition be received within the fee schedule.

(2) That a competent and clearly defined donor support program be established in each transplant region which will assume responsibility for the continuing maintenance of the non-living donor immediately upon notification by the referring physician, and that appropriate funding be made available for this service.

8.3 TECHNICAL CONSIDERATIONS IN ORGAN DISTRIBUTION

From the data currently available, it is evident that cold storage represents a considerable saving in fixed and personnel costs by comparison with machine perfusion, and permits greater flexibility in organ transportation while exhibiting comparable efficacy as measured by graft survival.

It is proposed that the regional transplant centres adopt a uniform policy of organ storage based upon the most cost effective technique, unless machine perfusion can be clearly proven necessary to provide optimal graft survival.

As well, a rapid and efficient system of organ distribution should be adopted to permit transportation of the kidney with minimal delay.

8.4 IMMUNOLOGICAL CONSIDERATIONS IN ORGAN DISTRIBUTION

The current evidence indicates that immunological presensitization and histocompatibility matching exert an important influence on graft survival, and hence on the efficiency of organ utilization and cost effectiveness of organ transplantation as a therapeutic modality.

It is proposed that these two factors be taken into consideration in developing a strategy for organ distribution, and that uniform policies and techniques for both tissue typing and cross-matching be established at participating centres.

8.5 ORGANIZATIONAL CONSIDERATIONS IN ORGAN DISTRIBUTION

It is evident that the current system of organ distribution, while permitting maximum use of procured organs, does not fulfill the additional requirements of improved graft survival and equitable distribution now considered essential.

It is proposed that:

1. A system of full organ sharing, based upon defined immunological parameters, be adopted between centres and regions.
2. That the incentives for organ retrieval be maintained by ensuring organ distribution in proportion to regional contribution.
3. That an appropriate system for funding be established to permit optimal development of all regional programs participating in organ retrieval.

8.6 ECONOMICS AND EFFICIENCY OF ORGAN RETRIEVAL

From the data presented, it is evident that organ retrieval in the Province of Ontario is highly cost effective. The cost of retrieval per kidney from the non-living donor approximates between 29.5 percent and 49.7 percent of the mean cost of the comparable procedure in the United States. The efficiency of organ retrieval, and hence of kidney transplantation, while exceeding that of Canada as a whole, is considerably inferior to that of the major American centres surveyed. As measured by the procedures performed per million population, mean comparative efficiency of kidney retrieval and kidney transplantation in Ontario are 59.8 percent and 64.0 percent respectively, compared with the American centres surveyed.

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ORGAN DONATION IN THE EIGHTIES:

A BLUEPRINT FOR SUCCESS

LIVING RELATED DONOR SUBCOMMITTEE

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TABLE OF CONTENTS

PAGE

1.0 INTRODUCTION 180

2.0 OBJECTIVES 180

3.0 LITERATURE REVIEW

3.1 Professional

3.1.1 Attitudes Towards Living Related Donation 181
3.1.2 Perception of Risk 181
3.1.3 Methods of Donor Recruitment 182
3.1.4 Living Related to Emotionally Related Donation 182
3.1.5 Incentives/Rewards 183

3.2 DONORS

3.2.1 Attitudes Toward Living Related Donation 184
3.2.2 Non-Donors' Attitudes 184
3.2.3 Awareness of Living Related Modality 185
3.2.4 Incentives/Disincentives 186

4.0 METHODOLOGY

4.1 Sample Selection 187

5.0 FINDINGS: PROFESSIONAL

5.1 Perceived Risks for Living Related Donor/Recipient 188
5.2 Donor Recruitment and Communication 191
5.3 Donor Source Preference 193
5.4 Rewards and Reimbursement 196

6.0 FINDINGS: PATIENT

6.1 Demographic Information 198
6.2 Awareness of Living Related Modality 199
6.3 Perceived and Actual Risks 199
6.4 Considerations and Attitudes to LRD 201
6.5 Emotionally Related Donation 204
6.6 Rewards and Reimbursements 205
6.7 Non-monetary Rewards 206

7.0 DISCUSSIONS AND CONCLUSIONS

7.1 Donor Recruitment and Communication 208
7.2 Patient Awareness of LR Modality 208
7.3 Perceived Risks for LR Donor 209
7.4 Patients' Perceived and Actual Risks 209
7.5 Professionals' Donor Source Preference 210
7.6 Patient Attitudes to LRD and ERD 211
7.7 Reward and Reimbursement - Professional 211
7.8 Reward and Reimbursement - Patient 211

1.0 INTRODUCTION

This report details the research of the "Living Donor Committee", one of the five sub-committees comprising the Provincial Task Force on Organ Donation. The aim of the survey research conducted by this sub-committee is to provide an understanding of the attitudes and feelings of renal/transplant unit professionals and patients, including donors, recipients, potential donors (family members) and potential recipients surrounding living-related donation. Living-related donation at the present time represents only 20% of all kidney transplants. Through examination of these specified objectives the committee has been able to identify barriers that might exist with respect to living donation.

2.0 OBJECTIVES

Renal transplant unit professionals were asked:

a) to document the incidence of living related donation

b) to outline attitudes toward, and perception of risk involved with, living related and emotionally related donation

c) to specify methods of donor recruitment

d) to identify attitudes toward rewards/incentives.

Patients in the sample were asked:

a) to specify sources of information and awareness of the living related modality

b) to identify perception of risk(s) to the donor and risks which became evident as a result of donation

c) to describe attitudes towards financial rewards and reimbursement, and to identify possible sources of such payments

d) to identify feelings towards emotionally related (not genetically related) donation.

3.0 LITERATURE REVIEW

3.1 PROFESSIONAL

3.1.1 Attitudes Towards Living Related Donation

The literature cites varied professional attitudes concerning living related donation (LRD). Some professionals view LRD as unethical since the "sacrifice" of a normal organ jeopardizes the health of the living donor and is contrary to the medical norm "First of all, do no harm".[1] As well, some professionals feel there is the possibility of coercion and covert pressure exerted by the family so as to promote involuntary consent on the part of the donor.[2]

On the other hand, advocates of related donation refer to the superior rate of non-rejection as compared with cadaveric transplants. Immediate and long-term morbidity rates are low and therefore LRD is an "acceptable risk" for informed and motivated relatives. The authors further state their endorsement of LRD even if the success rates were not superior in order that patients not be denied transplantation because of cadaver shortages.[3]

3.1.2 Perception of Risk

Hamburger and Crosnier (1968) state that risks to the donor are perceived by professionals as being "slim". However, it is also felt that potential donors must be informed concerning the degree and type of risk that may occur.[1] Education and understanding of the transplant process have been identified as important precursors of a realistic outlook and informed consent.[4].

3.1.3 Method of Donor Recruitment

Methods employed to "recruit" living related donors also vary in the literature from being part of a routine selection procedure in which ambivalent/pressured donors are rejected; to the opposite case in which the potential donor finds donation to be a difficult procedure and must offer several times. Recruitment methods differ and there is generally no consensus regarding the medical profession's effort to secure living related donors.[1]

3.1.4 Living Related to Emotionally Related Donation

It has been reported that the consensus among some transplant units regarding LRD is that such donations are acceptable between sibling and parent/child exchanges. As well, living unrelated donations are acceptable if an affectionate bond exists; that is, donor and recipient are emotionally related.[5]

Some professionals have proposed that donor sources should include emotionally related donation (ERD) depending on situational circumstances.

> An absence of other donor sources, the existence of preformed antibodies or priority on the transplant list all seem to us (the authors) to be compelling reasons to consider the use of the emotionally related donor.[6]

One method of alleviating the kidney shortage from cadaver sources would be the use of emotionally related donors. However, a lack of clear norms governing such situations has discouraged tapping this source.[1] Consequently, the literature demonstrates transplant centres' reluctance with ERD due to ethical considerations and citing similar rejection rates to cadaveric sources. Fellner and Schwartz[2] reported that both McGeown (1968) and Nahum (1968) felt ERD to be completely unjustified as the transplant would not offer a greater likelihood of success than cadaveric.

In contrast, Lawton states "...there is no reason for not using LNR donors if there is a need" and suggests that with proper matching of donor/recipient, some results will be better than cadaveric although less than LRD.[5] As reported by Burley and Stiller[7] Fellner and Schwartz (1971) have stated that the medical profession's rejection of LNR donation appears to be "'unscientific, emotional, prejudicial'" and out-of-step with public opinion.

Abt Associates of Canada[8] in the project survey Public Attitudes to Human Organ Donation report that the public has positive attitudes toward living related donation. In regards to living unrelated donation (a stranger), it has been reported that 19% of the public would donate, 33% were not sure and 46% would not donate to a stranger. The researchers' conclusion was that the public has less aversive attitudes towards living unrelated donation than the medical profession.[9]

Nevertheless, the medical profession has deemed ERD as unacceptable in regards to the risk: benefit ratio[10] even though unrelated living donors provided 14.5% of transplanted kidneys for 14 years prior to 1967 (U.S.A.). Katz and Capron[11] state the non-use of such donors since 1969 reflects the physicians' choice in policy-making rather than an increased availability of organs from other sources.

3.1.5 Incentives/Rewards

Katz and Capron[11] have reported professionals' fear that payments for organs would lead to decreased altruism among donors and recipients' next of kin. In general, the literature demonstrates that professionals fear exploitation of people who would be induced to assume a physical harm for monetary harm.

3.2 DONORS

3.2.1 Attitudes Towards Living Related Donation

Positive attitudes have been noted on behalf of living related donors in several studies. At four to seven years post-transplant, one study noted that donors whose donated kidneys had been rejected were somewhat more regretful (17%) towards donation than donors with successful transplants. Although siblings as donors were somewhat more likely to express negative reactions than parents, in general donors remained positive and perceived themselves as "better" people for having donated in attempts to help improve another's life.[12]

In another study, Simmons[13] reported positive attitudes of donors at 5 to 9 years post-transplant with both successful and unsuccessful transplants. Negative reactions to LRD were rare but not absent. A third study[14] concerned living related donors' regret with donation one year after a successful transplant. Only 1% stated uncertainty with regards to the decision to donate if presented with the choice again. All other respondents stated they would donate again although 2% of these donors indicated feeling a lack of appreciation for their donation. The researchers concluded that "significant psychological long-term costs seem to affect only a very small number of the donors".[14]

3.2.2 Non-donors' Attitudes

In contrast, non-donors reportedly have less favourable attitudes towards donation and transplantation. They also have a greater tendency to minimize differences between cadaveric and live-related donation in terms of successful transplant. Non-donors (37%) stated they perceive no difference in success rates between these two modalities as compared to 5% of donors.[15] The authors propose that the less favourable attitudes of non-donors may result from their perception of statistics and risks.

> The non-donors are less likely to believe that a sacrifice of their own kidneys would help the patient more than would the use of a cadaver organ.[15]

These researchers state potential donors' fear of risking their future health and fear of surgery may prevail throughout the issue of donation and contribute to non-donation. Such fears could potentially be alleviated through discussions with, and information provided by, the medical profession. In fact, anxieties experienced by potential donors were often reinforced through family physicians' expression of disapproval. Forty-nine percent of non-donors reported opposition from their family doctor in comparison to 32% of donors. Thus it appears the attitude of some doctors is related to the incidence of living related donation.[15]

It has been stated that in some

> ...transplant centres where less emphasis is placed by the physicians on the need and advantage of related donors, the extent of volunteering would be less. However, where the need is stressed, the majority of family members are willing to make this major sacrifice to save the life of their dying relative.[16]

In fact, the authors report that 57% of all eligible relatives donated or volunteered (tested, but medically ineligible) to donate their kidney.

3.2.3 Awareness of Living Related Modality

Richardson's research[17] concerning cadaveric donation states that the most frequent source of information was the media (television, radio, newspaper) while physicians were the most infrequent source of information. It will be of interest to note if the present survey obtains similar findings in regards to LRD and sources of information concerning this modality.

3.2.4 Incentives/Disincentives

The Abt Associate study entitled Public Attitudes to Human Organ Donation identifies the public's attitudes towards incentive/reward issues. The report states that the public opposes the buying and selling of organs in which a "profit motive" may affect donation. Findings also indicate opposition to recognition for donation as the public perceives donation as a personal matter and a private decision.[18]

Lawton[5] also states opposition to financial rewards for donation but endorses financial reimbursement in order that costs do not become a disincentive.

> ...It is imperative that he or she (the donor) is not penalized financially for this heroic act. This donation should not cost the donor any personal outlay of funds but it is essential that this donation be made spontaneously without direct financial compensation...[5]

It will be of interest to note how donors and recipients feel towards such reward and incentive issues. Respondents may agree with public opinion and oppose potential incentives such as public recognition. However, if has been reported that some donors (5% to 10%) feel they receive too little appreciation and recognition from the recipient and other family members.[14] Therefore, determination of donors' feelings surrounding public and private (family) recognition may provide some incentives for kidney donation. Thus, reward, reimbursement and incentive issues will be addressed in the committee's research.

4.0 METHODOLOGY

4.1 Sample Selection

a) Professionals

The study involves a sample of 77 professionals from the Renal/Transplant Units of the following eight hospitals:

1. Grace Hospital, Windsor
2. Victoria Hospital, London
3. University Hospital, London
4. Ottawa Civic Hospital, Ottawa
5. Toronto Western Hospital, Toronto
6. Toronto General Hospital, Toronto
7. St. Michael's Hospital, Toronto
8. Hospital for Sick Children, Toronto

Selected participants included: Transplant Surgeons (13), Nephrologists (28), Dialysis Unit Directors (9), Nephrology Social Workers (8), Dialysis Unit Head Nurses (14), Transplant Coordinators (or Patient Coordinators) (7), and Registered Nurses on the unit (7). It should be noted that 9 people act in dual roles.

b) Patients

The second aspect of this research involved a sample of 118 patients, including donors, recipients and potential donors/recipients. Samples were obtained from these same units with the cooperation of the Chiefs of Nephrology. Persons under 18 years of age were excluded and consequently only professionals were surveyed at The Hospital for Sick Children, Toronto. The number of respondents from the Ottawa area was 16, 49 respondents were involved with Toronto hospitals and 53 respondents resided in Southwestern Ontario. On average, 17 patients per hospital responded to the request to participate (X = 16.6).

5.0 FINDINGS: PROFESSIONAL

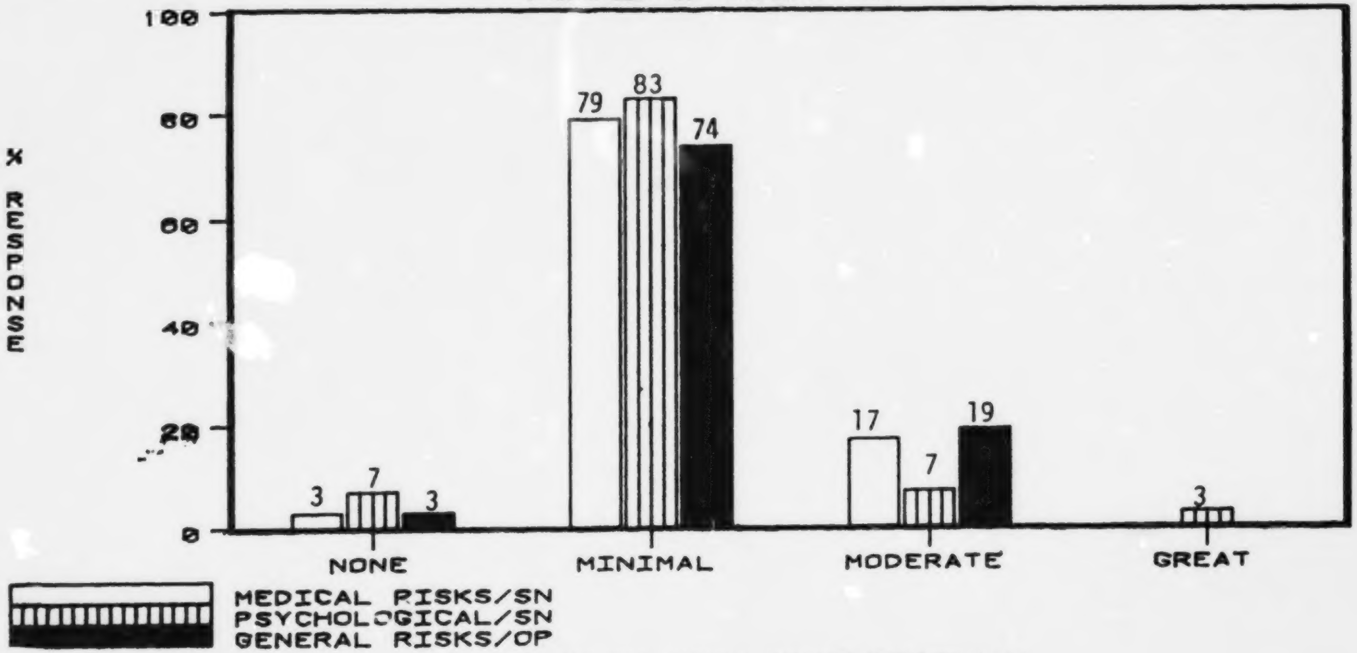
The following findings are based on data obtained from the professional sample and are subdivided into two groups of: Surgeons and Nephrologists and Ontario Unit Professionals (including Social Workers, Nurses, Transplant/Patient Coordinators). The response rate of Surgeons and Nephrologists was 71% (n=29) and for Ontario Unit Professionals it was 86% (n=31) (total: 78%).

5.1 PERCEIVED RISKS FOR LIVING RELATED DONOR/RECIPIENT

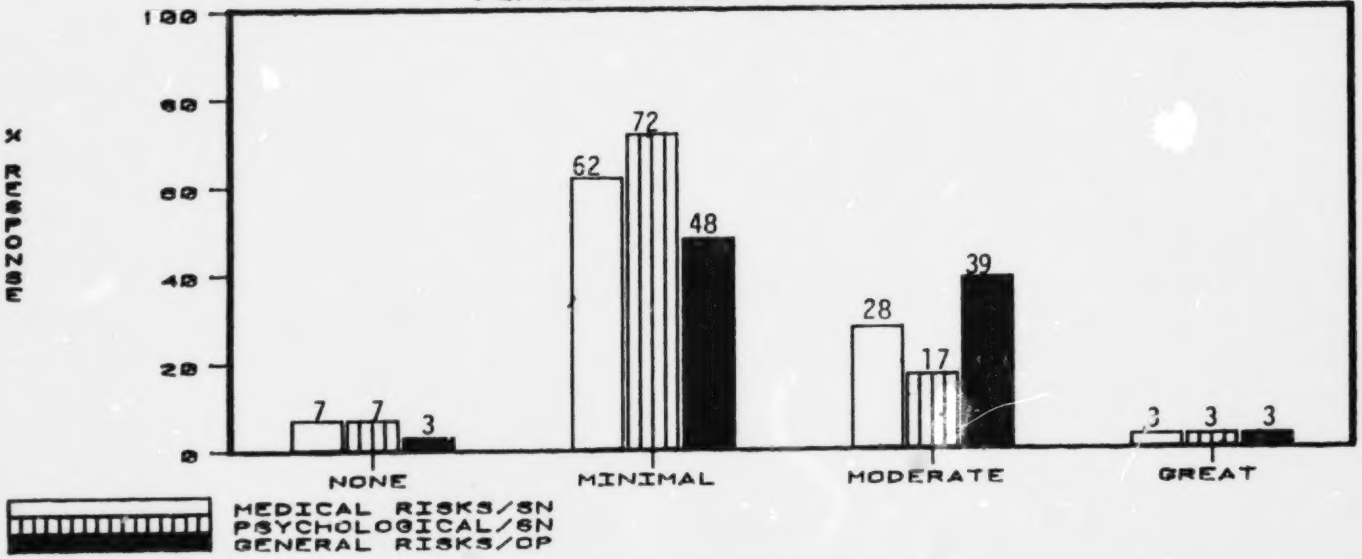
As shown in Tables 1 and 2, Surgeons and Nephrologists feel medical and psychological risks are slightly greater for recipients than for donors. They identified surgical risks and long-term health risks for the donor in comparison to the risk of kidney rejection with accompanying psychological/emotional risks for the recipient.

In comparison to the doctors, other professionals perceive a similar degree of risk for both donors and recipients but perceive the type of risk differently. For example, other professionals feel long-term health risks for the donor to be much lower than doctors (28% : 73%) whereas psychological risks are perceived to be much higher (52% : 19%). Other professionals also perceive surgical risks for the recipient (54%) to be much greater than the surgeons and nephrologist (23%). Both groups perceive a similar degree of psychological risks for the recipient such as guilt with transplant failure and/or "taking" the kidney, yet other professionals cite the risk of kidney rejection to be much higher (32%) than the doctors (18%). Both samples also referred to the risk of immunosuppression such as increased risks of infection and potential hazards to long-term use of Cyclosporine.

TABLE 1



HEALTH CARE PROFESSIONALS
PERCEIVED RISKS FOR DONORS



HEALTH CARE PROFESSIONALS
PERCEIVED RISKS FOR RECIPIENTS

TABLE 2

PROFESSIONAL PERCEPTION OF RISKS FOR DONORS

	SURGEONS/NEPHROLOGISTS	OTHER PROFESSIONALS
Surgical	57.7%	80.0%
Long-term Health	73.1%	28.0%
Psychological/Emotional	19.2%	52.0%
"No significant risks"	3.8%	0%

PROFESSIONAL PERCEPTION OF RISKS FOR RECIPIENTS

	SURGEONS/NEPHROLOGISTS	OTHER PROFESSIONALS
Surgical	22.7%	53.6%
Long-term Health	4.5%	0%
Psychological/Emotional	54.5%	60.8%
"No significant risks"	9.0%	0%
Kidney Rejection	18.1%	32.2%
"Usual risks"	22.7%	10.8%
Risks of Immunosuppression	9.1%	25.1%

5.2 Donor Recruitment and Communication

As indicated, professionals overwhelmingly identified the first source of donor "recruitment" as Nephrologists (97%) whereas involvement of other professionals combined was less than this source (Table 3). The high degree of consistent responses illustrate conformity throughout the various renal units in regards to the employed method of recruitment. Upon closer observation, all hospitals identified the Nephrologists as the first source of recruitment excepting the Hospital for Sick Children in which the Nephrologists and Social Workers were identified with equal frequency. Professionals identified other means as well; for example, approximately 16% of respondents stated the patient and/or family would approach the medical staff and 19% stated the patient approached the family.

Nephrologists (71%) were also identified as the primary source of informing the recipient and family members throughout the process of transplantation followed closely by a "team approach" (67.7%) (Table 4). Surgeons and Nephrologists basically agreed with these two sources, and the frequency of use.

TABLE 3: METHOD OF DONOR RECRUITMENT

ONTARIO UNIT PROFESSIONALS:	
1. Nephrologist	96.8%
2. Social Worker	38.7%
3. Nurse	35.5%
4. OTHER - Transplant Coordinator	16.1%
OTHER MEANS:	
5. Patient/family approaches staff	16.1%
6. Patient approaches family	19.3%
7. Post Information	6.5%
8. Informal network (inter-family communication)	3.2%

TABLE 4: HOSPITAL PRACTICE RE: COMMUNICATION WITH RECIPIENT / FAMILY

	Other Professionals	Surgeons/Nephrologists
1. Nephrologist	71.0%	65.5%
2. Team Approach	67.7%	72.4%
3. Social Worker	58.1%	41.3%
4. Nurse	48.4%	17.2%
5. Transplant Team (or surgeon)	45.2%	41.3%
6. Family Doctor	3.2%	0%
Other:		
7. Transplant Coordinator	9.7%	3.4%
8. Clinical Nurse Specialist	3.2%	0%
9. Unknown	3.2%	0%
10. Not applicable	3.2%	0%

5.3 Donor Source Preference

As indicated in Table 5, Surgeons and Nephrologists support LRD as a preferred modality (All hospitals = 50%; Adult only = 61%) as do other professionals.

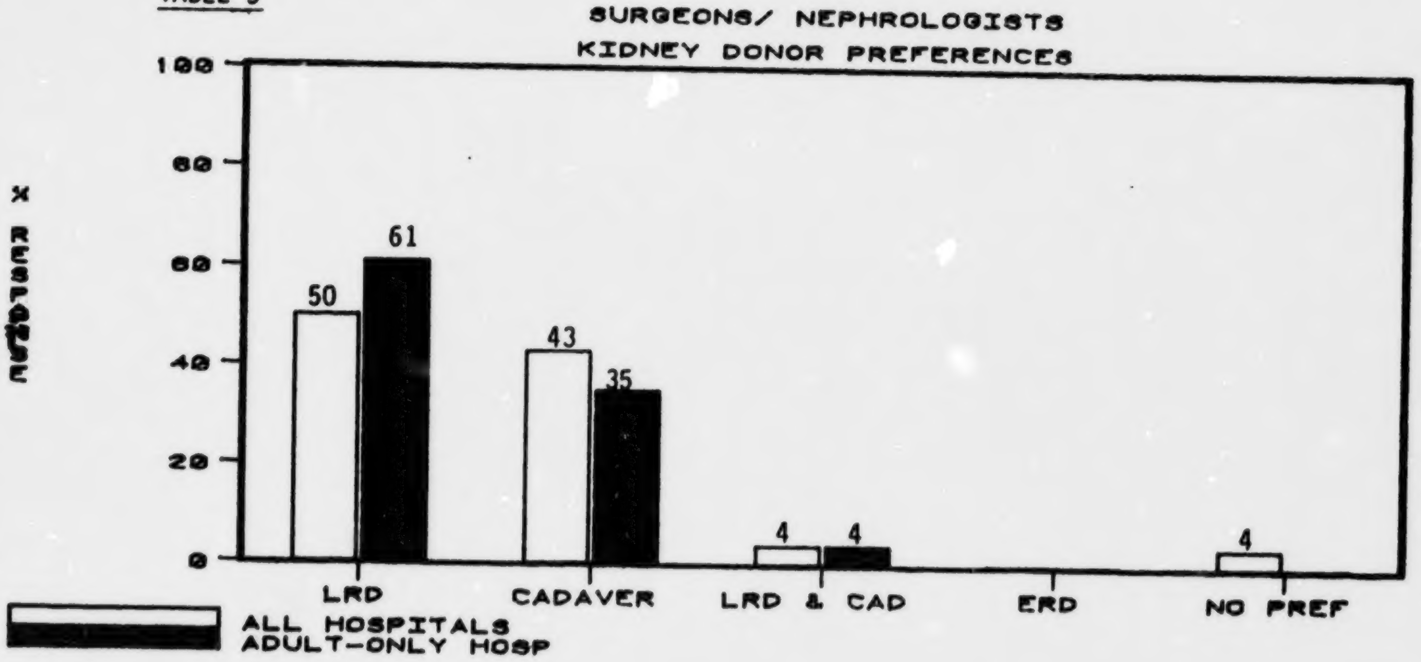
In contrast, ERD is generally not favoured. 89.5% of physicians agreed with the statement that "Living unrelated donation (is) least favoured as compared with cadaveric and living related (modalities)" primarily because success rates are no better than with cadaveric transplants. However, some physicians responded positively towards ERD by stating its use would reduce the numbers waiting for a transplant whereas others emphasized expediency should not take such precedence.

Ontario Unit professionals did not favour ERD since graft survival is not superior to those of cadavers. When positive towards ERD, professionals perceived the factors of expediency, reduction of the number on current waiting lists and ERD as an "improvement of (dialysis patient's) life".

Attitudes of both samples towards ERD in an exploratory pre-/post-test remained largely unchanged. If any change was noted, it was a very slight movement towards a more conservative orientation. However, such a minimal shift is certainly not considered conclusive and any detailed correlation between such attitudes and impact of information distribution would require further study.

However, in spite of opposition to ERD, approximately 47% of doctors would not object to its use in some circumstances. Also, 68% feel ERD would reduce the kidney shortage even if only minimally (Table 6). Thus physicians agree kidney shortages could be alleviated with the use of emotionally related donors. However, most respondents oppose such action (54%); some citing (i) similar rejection rates to cadaveric sources, (ii) legal issues/concerns, and (iii) ERD would only be considered as a last resort in which both LR and cadaver sources were unavailable (Table 6).

TABLE 5



OTHER PROFESSIONALS

Agreement with LRD statements per 100%:

1) "favored over cadaveric because of better genetic match"	64.5%
2) "unfavored because no benefits to donor"	0%
3) "somewhat favoured as donor gains psychological benefit"	12.9%
4) "favoured because most readily available"	35.5%
5) "somewhat unfavoured because potential medical risks to donor"	12.9%
6) OPEN - in general, favour and support LRD	25.8%
7) OPEN - partial support/mixed feelings	6.4%

TABLE 6: SURGEONS / NEPHROLOGISTS RESPONSES

---

i) Provided a living unrelated donor is both physically and psychologically suitable and no ulterior motives to donation are evident, would you hold any objections to such a transplant?

YES = 53.6%
NO = 46.4%

(*NOTE: Living unrelated is defined as emotionally related either through marriage or friendship).

ii) Do you think an increased use of living unrelated donors would close the gap between the numbers of kidneys needed and the present shortage?

YES = 68.0%
NO = 28.0%
There is no present shortage = 4.0%

As mentioned in the literature review, the public has less aversive reactions to living unrelated donation than the medical profession. Therefore, surgeons and nephrologists were asked if they think public opinion differs from professional opinion regarding ERD. Almost twenty-nine percent (28.6%) felt that public opinion does not fully differ from professional opinion. Fifty percent said they did not know. They were then asked whether this knowledge affected their view to transplant practice.

Almost 88% of doctors responded "no" and comments ranged from:

1. "Public opinion is too emotional".
2. "The public is not the most informed group".
3. "Public opinion is now reasonably educated in the merits of kidney transplantation".
4. "Rejection rates don't justify public opinion".
5. "Not different".
6. "Both vary widely".

Only one respondent stated agreement with the public and felt ERD can be justified with current therapy. However, in the post-test 6% felt perhaps the medical profession should modify its stance and become more accepting of ERD whereas 6% reacted by stating strong disagreement with the concept of ERD. The attitude of the vast majority (88%) of physicians remained much the same.

5.4 Rewards and Reimbursement

a) Surgeons and Nephrologists

Surgeons and Nephrologists were asked if they felt donors are adequately financially reimbursed for their involvement associated with donation. Almost sixty-six percent (65.5%) answered "there is no reimbursement". Just under 14% said there was not adequate reimbursement; 3.4% indicated that there was adequate reimbursement. Respondents suggested three areas of reimbursement to be provided by the government: financial losses due to time away from work; travel costs; general "incurred costs" resulting from the donation.

Surgeons and Nephrologists were then asked if they felt donors should be financially rewarded regardless of any reimbursement for their organ donation. Just under 14% said there should be financial reward, but qualified their responses by stating the reward should not be for profit but rather a form of reimbursement; seventy-nine percent said there should be no financial reward; nearly seven percent (6.9%) did not respond. Respondents opposing the utilization of monetary rewards fear the potential abuse of the system by becoming an "organ market" in which organs would be bought for a price. They feel donation should be an altruistic and voluntary act without inducement to assume a physical risk.

Surgeons and Nephrologists were also asked if donors should be rewarded in other ways such as public recognition. Thirty-one percent agreed that there should be such recognition; 62% disagreed; 7% did not respond. Physicians responding "no" to this question perceive donation to be a personal decision and private undertaking between two people. Therefore, a form of "reward" is felt to be unnecessary. Those supporting some form of reward" specified the following forms: reimbursement of costs; annual event (i.e. a dinner) for donors/recipients; individual option for donor to publicize donation.

b) Ontario Unit Staff

Ontario Unit Professionals were asked if they felt donors should be financially rewarded for their organ donation. Seventy-four percent responded "no"; almost twenty-six percent (25.8%) replied "yes". As with the physicians, other professionals stating "no" oppose the selling of organs and fear the formation of an "organ market". They also feel the act of donation should be performed for love or altruistic reasons. Of those responding positively to this issue, 87.5% qualified this reward to be a form of reimbursement only. Of these same respondents, 62.5% specified OHIP as the source of such payments followed by a government fund (12.5%) and the Kidney Foundation or Social Work Fund (25%).

Ontario Unit Professionals were asked if they felt donors should be rewarded in other ways such as public recognition. Sixty-one percent responded "no"; 39% responded "yes". Respondents stating "no" specified the following reasons: donation is a personal/private undertaking (37.5%); donor should feel rewarded by the act itself (37.5%); confidentiality of donor should be respected from the public (25%). Of participants responding "yes", 55.6% specified public recognition should be an individual option for the donor whereas 33.3% indicated donation should be recognized in some form either from the media, transplant centre or Ministry of Health. One respondent also suggested an annual event for donors and recipients.

In addition, the Ontario Unit Professionals were asked if they felt donors are adequately reimbursed for their costs associated with donation. Just over forty-five percent (45.2%) answered "yes", and the same number said "no". Almost ten percent (9.6%) did not respond. Those stating "no" specified that loss of wages, travel and accommodation costs, and extra-billing (above OHIP) should be reimbursed.

6.0 FINDINGS: PATIENT

The following findings are based on data from the patient sample with four groups of (1) donor (n=43), (2) potential donor (n=13), (3) recipient (n=51), and (4) potential recipient (n=11). (Total: 118)

6.1 Demographic Information:

There was a slightly greater number of male (55.1%) participants than females (44.9%) with an age range of 18 to 71 years. Generally donors were slightly older ($\bar{x}$ = 44) than recipients ($\bar{x}$ = 32) which could possibly be a result of parent-to-child donation.

The vast majority of all respondents were married (64.4%) followed by those who have never been married (28.8%). Twice as many recipients as donors have never been married. Other respondents' marital status included separated (4.2%) and widowed (2.5%). The largest number of respondents, regarding level of education, had completed secondary school (33%) whereas 27% had completed public school. Twenty-six percent had completed college and 14% had a university education. Recipients generally had a slightly higher level of education than donors as 45% had a college or university education compared to 39% of donors.

Almost 81% of all participants were born in Canada and three-quarters of all respondents had an ethnic background of English-Canadian (48%), French-Canadian (7%), Dutch (9%), British (7%) or German (6%). Approximately 11% stated they had no religious affiliation in comparison to those identifying Catholic (37%), Anglican (13%), United (10%), "Protestant" (8%), Presbyterian (5%), Lutheran (3%), Baptist (4%) and "other" (9%). Fifty-four percent of those surveyed are presently employed full-time whereas 14% are unemployed. Eleven percent are homemakers, 6% are employed part-time while 10% are attending an educational facility. Retired respondents constituted 3.4% of the sample while 0.8% stated they were "never employed".

Urban dwellers constituted 85% of the sample whereas 11% reside in a rural area and 4% live on a farm. Almost 46% stated travel time to the transplant centre was not inconvenient at all compared to 40% who stated "somewhat inconvenient" and 14% who felt the location to be very inconvenient.

6.2 Awareness of Living Related Modality

Donors identified themselves, the potential recipient and medical staff as the major sources of the idea regarding donation. Approximately 38% of all donors stated they were informed of the potential for donation by the recipient and/or medical staff and/or obtained the information themselves. (Table 7)

6.3 Perceived and Actual Risks

Perceived Degree of Risk for Donor

	Donor (prior to transplant)	Potential Donor	Recipient	Potential Recipient
None	41.9	7.7	13.7	0
Minimal	46.5	30.8	60.8	63.6
Moderate	11.6	46.1	19.6	36.4
Great	0	15.4	5.9	0

As mentioned in the literature review, potential donors' fears appear to centre on medical and long-term health risks. This trend is validated by noting actual donors' perception of risk type prior to transplant (Table 8) which corresponds with the physicians' identification of medical/surgical risks and long-term health risks. However, post-transplant 61% of donors stated no risks had become evident with minimal medical complications or impaired health. The most evident risks were of a financial nature (18.6%) and loss of time from work (25.6%). These costs could explain donors' somewhat greater endorsement of reimbursement (re: Rewards and Reimbursement section) than potential donors. However, reflecting the nature of actual costs, a greater emphasis regarding loss of work time and finances would be an appropriate endeavour by physicians.

TABLE 7

AWARENESS OF LR MODALITY/SOURCE OF INFORMATION

i) DONOR:

Where did the idea to donate your kidney come from?

1.	Medical Staff	37.2%
2.	Social Worker	2.3%
3.	Family Doctor	2.3%
4.	Potential Recipient	37.2%
5.	Other Family Members	11.6%
6.	Media	4.7%
7.	Other - Self	39.5%

ii) RECIPIENT:

How did you become aware of living related donation prior to the transplant?

1.	Medical Staff	68.6%
2.	Family Doctor	21.6%
3.	Social Worker	9.8%
4.	Family Members	29.4%
5.	Own Initiative	21.6%
6.	Media	17.6%
7.	Other - Donor	7.8%

iii) POTENTIAL RECIPIENT:

What was your source of awareness re: LRD as a form of treatment?

1.	Medical Staff	54.5%
2.	Family Doctor	9.1%
3.	Social Worker	0%
4.	Family Members	0%
5.	Own Initiative	36.4%
6.	Media	0%
7.	Other - Other Patients	9.1%

TABLE 8

PERCEIVED AND ACTUAL TYPE OF RISK FOR DONORS

	PERCEIVED RISK				ACTUAL RISK (post-tx)
	DONOR	POTENTIAL DONOR	RECIPIENT	POTENTIAL RECIPIENT	
Medical complications	39.5%	69.2%	51.0%	54.5%	4.7%
Impaired health	16.3%	30.8%	47.1%	36.4%	4.7%
Loss of time at work	18.6%	7.7%	45.1%	27.3%	25.6%
Financial losses	2.3%	23.1%	29.4%	27.3%	18.6%
Reduced social/rec. activities	2.3%	0%	19.6%	9.1%	9.3%
OTHER- psychological/ emotional	2.3%	7.7%	5.9%	0%	2.3%
OTHER - job change	0%	0%	0%	0%	2.3%
NONE	34.9%	7.7%	13.7%	0%	60.5%

6.4 Considerations and Attitudes to LRD

The overwhelming major considerations identified by both donors and potential donors was a feeling of love/caring for the recipient and a belief in helping others (Table 9). All respondents identifying "pressure" specified a feeling of obligation or responsibility to help a family member.

TABLE 9: LIVING RELATED DONATION

CONSIDERATIONS IN LR DONATION

DONOR	FACTOR/CONSIDERATION	POTENTIAL DONOR
11.6%	Recognition/appreciation from family members	0%
11.6%	Encouragement from Medical staff	15.4%
20.9%	Encouragement from recipient	7.7%
7.0%	Encouragement from other family members	0%
95.3%	Feelings of love/caring from recipient	69.2%
7.0%	Religious belief/obligation	7.7%
18.6%	Parental duty	7.7%
0%	Improve previous family differences	0%
41.9%	Belief in helping others	69.2%
7.0%	"Pressure"	7.7%
4.7%	Other	0%

Concerning misgivings and second thoughts prior to donation, donors most often referred to fear of surgery/pain although fears of impaired health and transplant failure were also mentioned. (Table 10)

Recipients apparently had a greater frequency of "second thoughts" concerning the donation and most often specified a fear that donation would jeopardize the donor's future health and fear of transplant failure. In other words, the recipients are concerned that donors have taken such a risk which results in rejection. (Table 10)

Nevertheless, positive feelings towards LRD were noted across all sub groups. All but one donor stated that he/she would undergo the donation process again if they previously knew what the actual experience would entail. As well, the three other sub-groups rated their feelings towards LRD as reported in Table 11.

TABLE 10: MISGIVINGS/"SECOND THOUGHTS" RE: LRD PRIOR TO DONATION

	Donor	Recipient	Potential Recipient
YES	14.0%	64.7%	54.5%
NO	86.0%	35.3%	45.5%

TABLE 11: FEELINGS TOWARD LIVING RELATED DONATION

	Recipient	Potential Recipient	Potential Donor
Very Positive	76.5%	45.5%	30.8%
Positive	19.6%	45.5%	53.8%
Undecided	2.0%	9.1%	15.4%
Negative	2.0%	0%	0%
Very Negative	0%	0%	0%

Such positive responses are not surprising when one considers that all but one participant had successful LR transplants ranging in time from one month to 17 years ($\overline{x}$ = 3.3). As well, 12% of recipients had had a previous (one or more) cadaveric transplant. Thus respondents feel their positive view of LRD is warranted based on the high acceptance rate and consequent improvement in lifestyle experienced by the recipient.

6.5 Emotionally Related Donation

When donors were asked if they would consider donation towards a non-related recipient to whom they were emotionally attached, eg. spouse or close friend, 95% indicated with affirmatives. In contrast, only 26% would have considered live donation towards a non-related recipient such as a stranger. Those who would not have considered such a donation emphasized the lack of emotional bond although 27% qualified their response by stating they would donate their organs with death.

As illustrated in Table 12, ERD tends to be favourably supported across all patient sub-groups. However, a few patients qualified their reponse by stating "spouse only". Nevertheless, positive attitudes are noted on behalf of patients. Such data when compared to the data of physicians' attitudes emphasizes the previously acknowledged statement that physicians have more conservative attitudes towards such donations.

TABLE 12: ATTITUDES TOWARDS ERD

EMOTIONALLY RELATED DONATION

	Recipient	Potential Recipient	Potential Donor
Very Positive	52.9%	18.2%	15.4%
Positive	21.6%	63.6%	53.8%
Undecided	17.6%	9.1%	30.8%
Negative	7.8%	0%	0%
Very Negative	0%	9.1%	0%

6.6 Rewards and Reimbursements

Donors were asked to specify financial costs incurred as a result of their donation and the amount of reimbursement received. Financial costs included transportation (40%), accommodation (9%), post-operative care (5%), and "other" costs such as financial losses from work (23%) and extra billing by physicians/hospital (14%). One-third of the donors felt they had no financial costs incurred. Transportation costs at times were exorbitant as distances included Britain and the Maritimes. Donors who identified extra billing stated they had not been informed prior to the operation of additional costs for the surgeon and/or hospital room. Some anger towards medical staff was noted in regards to the manner in which these costs were charged yet all respondents experiencing this situation stated the cost itself would not have prevented their donation. Sixty-three percent of donors felt such costs should be reimbursed (Table 13) although some stipulated depending on financial need.

TABLE 13: REIMBURSEMENT FOR DONATION

	DONORS	POTENTIAL DONORS	RECIPIENTS	POTENTIAL RECIPIENTS
YES	62.8%	53.8%	84.3%	63.6%
NO	30.2%	46.2%	11.8%	36.4%
N.R.	7.0%	0%	3.9%	0%

The desired source of reimbursement was OHIP (Government insurance) followed by the recipient, irrespective of whether it was a recipient or donor response (Table 14). However, this source was at times qualified to be dependent on recipients' capability to financially reimburse. When asked whether organ donation should be rewarded financially other than reimbursement all respondents in the donor/potential donor category said no. Slightly more than 90% of the recipients and 82% of the potential recipients indicated a negative response.

TABLE 14: SOURCE OF DESIRED REIMBURSEMENT

	Recipient	Donor
None	11.8%	30.2%
OHIP	56.9	44.2
Recipient	13.7	4.7
Hospital	2.0	0
Other - Government Fund	7.8	4.7
- Kidney Foundation	3.9	2.3
- "Insurance"	3.9	4.7
- "Tax Credit"	0	2.3
No Response	0	7.0

6.7 Non-Monetary Rewards

When donors were asked "Did you receive adequate recognition for donation?", 93% responded "yes" often stating the recipient's good health and appreciation was all that was desired. However, some donors felt recognition by the medical staff to be inadequate in terms of both pre- and post-operative care. They specified a lack of immediate and long-term follow-up and perceived the situation as representative of the "non-caring attitude" of some medical staff with no demonstrated concern of potential medical complications and the donor's well-being. Although a limited number of donors mentioned such a situation, they added that they were not regretful of their donation even with such treatment. Thus it is important that the donor not be the forgotten participant in the post-transplant phase. As one recipient illustrated, a kidney would eventually have become available from a cadaver source and therefore the donor should be recognized for undergoing an elective operation to help improve another's life.

In comparison to the public's opposition concerning recognition for donation as stated in the literature review, donors also feel some form of recognition to be unnecessary (Table 15). However, both recipients and potential recipients agree that donors should be rewarded in some way. Those participants agreeing with non-monetary rewards specified several means of recognition (Table 16). Recipients' endorsement of public recognition and publicity was often comprised of two facets: (1) to recognize donors' contribution and (2) to increase public awareness of transplantation as a treatment modality.

TABLE 15: NON MONETARY REWARD

	Donor	Potential Donor	Recipient	Potential Recipient
YES	16.3%	7.7%	58.8%	72.7%
NO	83.7%	92.3%	39.2%	27.3%
No response	0%	0%	2.0%	0%

TABLE 16: SPECIFICATION OF NON-MONETARY REWARDS

1.	Recipient/family recognition (private)	10.5%
2.	Publicity (ie. media)	23.7%
3.	Medical Staff treatment (ie. follow-up/letter)	10.5%
4.	Public recognition (ie. document/plaque)	28.9%
5.	Annual event (ie. dinner/dance)	7.9%
6.	Donor's individual decision	10.5%

7.0 DISCUSSION AND CONCLUSIONS

7.1 DONOR RECRUITMENT AND COMMUNICATION

A uniform approach to recruiting living related donors appears to occur in the regions surveyed. There was a surprising 16% of professionals who identified that the patient or family approached the staff and 19% who stated the patient approached the family. This may represent a lack of adequate information provided by medical staff when the patient approaches end-stage renal disease. Clearly, information regarding potential living related donation should be provided to the family members of the potential recipient on the identification of the eventual need. The situation in which patients approached the family for transplantation would appear on the surface to be an unhealthy situation in which free choice on the part of the donor is unlikely to be able to occur. Again, this situation does not provide a barrier to transplantation but is something which, with standardized preparation of material for the donor family, could be improved.

7.2 PATIENT AWARENESS OF LIVING RELATED MODALITY

Approximately 38% of all donors stated they were informed of the potential for donation by the recipient and/or medical staff and/or obtained the information themselves. This is discordant with the view of the professionals who felt that the Nephrologists were the major source of information for the donors and, indeed, only one-fifth of professionals identified that donors were approached by the recipient. A higher percentage of recipients (69%) stated that they had been made aware by the medical staff of the potential for living related donation but 22% of recipients stated that they obtained information on their own initiative. More than one-third of them had also been informed by family members.

It seems reasonable to conclude that: (i) patients are not being adequately informed with respect to the potential of living related donation by the medical care team, (ii) they are obtaining their information at the present time as a result of family members, self-initiative, media and others, and (iii) that an unhealthy practice of the potential recipient approaching the potential donor exists in a significant number of cases. Better and more consistent education for all patients, and their families, who are in end-stage renal failure is necessary.

7.3 PERCEIVED RISKS FOR LIVE RELATED DONOR

It was the perception of the members of the Task Force at the start of the study that in some regions the perceived risk of living related donation might be significantly different than other regions. This, in turn, would have an effect on the likelihood of living related donation occurring. The survey has shown this not to be the case and indeed the perceived risks seemed to be shared from region to region. However, the psychological risks are perceived to be greater by the surgeon/nephrologist/professional than the patient sample. What is lacking is a comparison of the real risks that have been identified for both the recipient and the donor of living related donation by medical personnel. There is no evidence from this study that an absolute barrier to living related donation exists, but it is concluded that a common set of figures for predicting the actual risks, both medical and psychological, should be prepared and available to the members of the health care team, patients and family members.

7.4 PATIENTS' PERCEIVED AND ACTUAL RISKS

A consistent perception of the type of risk occurred with respect to donation although the perceived degree of risk varied. Some donors and potential donors (42%) actually perceived that there were no risks prior to transplantation. Now to some extent this is confirmed by the fact that 61% of donors felt they underwent no specific risk including medical complications, impaired health, loss of time from work etc. over their actual donation. However, ethics regarding informed consent indicate that it would be wrong to have donors agree to living donation if they perceive that there was no risk at all to them and this must reflect lack of education (either in the presentation of the knowledge or the perception of it). Once again, standardized information in pamphlet form should be prepared and accessible to all family members regarding the potential for living related donation and its accompanying risks.

7.5 PROFESSIONALS' DONOR SOURCE PREFERENCE

More than 50% of the surgeons/nephrologists and almost 90% of the other professionals stated a preference for living related donors as a source of donor kidneys. This was largely based, of course, on the perception that an increased graft and patient survival rate is attendant with that source of donation. This preference, therefore, is probably related to a genetic match as opposed to a 2-haplotype difference in which the results were likely to be the same as cadaveric. This reflected itself in the general aversion to using living unrelated donor kidneys. A full 90% stated that living unrelated donation was the least favoured source. In spite of this, however, 68% recognized that the gap between the number of kidneys needed and the shortage would be reduced, and 46% said that they would not object to such a transplant if no ulterior motives for donation were evident. A document which discussed emotionally related donation and outlined the rationale for utilizing this modality was distributed and a post-test indicated no change in the attitude of the professionals with respect to this modality.

The rights of the potential donors and recipients regarding access to information concerning ERD (emotionally related donation) were not explored in these surveys. However, the opinion of the professionals was not sensitive to public opinion indicating generally that it was fickle and uninformed. It seems unlikely, however, that with greater public awareness and with patients' greater involvement with decision-making regarding their care that the absolute barrier that has currently been erected by the profession to the use of emotionally related donors (such as spouses) will be able to be maintained. There seem to be, a priori, no rationale for refusing the donation of a spouse in which the graft survival rate is likely to be 70% when a similar donation from a sibling, who is 2-haplotype different and in which the graft survival is also 70%, is acceptable. The reason for the refusal can only be one of bias on the part of physicians/surgeons.

7.6 PATIENT ATTITUDES TO LRD AND ERD

The majority of individuals donated because they had feelings of love or cared for the recipient and believed in helping others. On the other hand, 65% of the recipients had misgivings about taking a live-related donation. The conclusion is that the present system provides for donation under a general category of altruism and indeed only 7% indicated that "pressure" was a consideration in their donation and all of those were their "own pressure" or a sense of obligation to help a family member. However the present system has been devised or evolved, it has resulted in a system in which relatives donate for the best of reasons and without a sense of pressure or coercion.

Virtually all donors and recipients indicated a positive attitude towards emotionally related donation, particularly spouse only. The obvious difference between this and the professionals' attitude reflects either a lack of information on the part of the potential donors and recipients or a strongly held bias on the part of the professionals. It would appear that a study into confirmation and resolution of this wide difference in opinions is required.

7.7 REWARD AND REIMBURSEMENT -- PROFESSIONAL

Forty-five percent of professionals (those usually associated with helping the patient resolve their financial difficulties) felt that donors are not adequately reimbursed. Travel and accommodation costs as well as extra-billing from surgeons should be reimbursed.

However, the predominant feeling expressed by the physicians, surgeons and other professionals was that reward or recognition is in general to be viewed negatively and that nothing which might encourage a "market" should be entered into.

7.8 REWARD AND REIMBURSEMENT -- PATIENT

Sixty-seven percent of donors felt they had financial costs incurred and some of these costs were considered to be exorbitant. In some instances the donors had not been informed adequately of such costs prior to transplantation including extra-billing by the surgical staff. However, in no instance would this have prevented donation. There was consensus that donors should be reimbursed for costs although, reflecting the altruism of the donors, 30% of them said that they should not be. The majority of individuals felt that government insurance should reimburse. Again, reflecting the very special nature by which this procedure is regarded, all donors and potential donors felt that no financial reward other than reimbursement should be given.

Ninety-three percent of donors felt they had received adequate recognition for the donation. However, this was primarily a result of recipient and family appreciation/recognition and was not attributed to recognition by the medical staff. Inadequate recognition by medical staff was underscored by several donors and the tenor was that they were the forgotten member of the procedure. The donors overwhelmingly felt that they should not be rewarded in ways other than financial reimbursement. However, the recipients felt otherwise and it may be that the recipients were more sensitive to what the donors really needed. The donors seemed unprepared, in their selfless and altruistic way, to identify these needs in this kind of survey.

The conclusion is that the donor must be reimbursed for actual costs, he/she must be informed of such costs ahead of time and extra-billing in this situation is clearly unacceptable. The medical staff must be more attentive to the needs of recognition that are required and rightfully deserved by the donor and some overt recognition (private or public) should occur in some carefully thought out way that protects the needs of privacy on the part of both the donor and recipient.

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SECTION IV

PUBLIC ATTITUDES TO HUMAN ORGAN DONATION

This study examined public attitudes towards human organ donations, in particular, the barriers and facilitators to kidney donation.

Six focus groups (n=60) were conducted, each lasting approximately two hours. Members of two groups were "donors", defined as persons who had signed the organ donor card attached to their driver's licence. Two groups were "non-donors", defined as persons who had not signed their driver's licence organ donor card. Non-donors included individuals opposed to donating (about one-third) and others who were ambivalent or who had just never thought about it. Two groups were parents of active car-driving children. As it turned out, one parents' group was mixed (donors and non-donors) and one consisted entirely of people who had not signed their donor cards, although a number of their children had signed. Respondents were urban, middle-class individuals, representing a wide variety of white and blue collar occupations. They were active car drivers of both sexes between the ages of 20 and 40 years. The parents ranged from 40 to 60 years.

A standard interview protocol was developed with appropriate modifications for each type of group. The facilitator provided as little factual information as possible to the groups and made no attempt to correct false perceptions or facts.

ATTITUDES TO ORGAN DONATION

General Knowledge of Organ Transplants

There were no differences between donors and non-donors in terms of their general awareness of the types of transplants available or the success rate of each type. Kidneys and corneas were believed to be the most successful transplants. Donors and non-donors were aware that a number of organs can be transplanted: heart, lung, kidney, liver, and cornea. There was also high awareness of bone marrow transplants. Respondents had no idea of the need for various organs and had virtually no knowledge of kidney disease.

Why sign the organ donor card?

The primary motivation for signing the organ donor card is to help someone else. Underlying this motivation is the belief that the status of the physical body after death is irrelevant. Donors had difficulty discussing this topic in detail. Their main response was simply "Why not?"

> If I'm dead, who cares? You hear of more and more people in need...why not? I won't need it.
>
> The body doesn't affect my spiritual needs when I die. I don't need it (the body).

We did not systematically explore the characteristics of organ donors, but the majority of donors we interviewed are also blood donors. Only three respondents knew someone who had kidney disease. People who signed their donor cards were no more knowledgeable about kidney disease or organ donation procedures than were non-donors.

The decision to donate was not made when the individual was confronted with the driver's licence. It occurred as a consequence of well-conditioned attitudes to the status of the body after death and the ethic of helping others. The driver's licence does provide a convenient way of recording a preconditioned decision, a solution that was not clear to respondents before this card became available.

Why would one not sign the donor card?

Among respondents who had not signed their organ donor cards, about one-third were opposed and about two-thirds were ambivalent or simply had not considered the question. Six major reasons were identified for not donating organs. Each is discussed below.

1. Hastiness of organ removal. Many non-donors worried that they might not really be dead when the organs were removed. They recalled media stories of persons thought to be dead who later revived. Organ removal eliminated that slim, second chance for life.

> You might not really be dead. Once the organs are gone,it's very final somehow.
>
> How fast is the decision made? Are you really dead? Who makes the decision?

The perceived speed of organ removal was also seen as interfering with the grieving process.

> I worry about being taken away quickly from my family. They will whisk you away from your family when they need a few more hours to grieve.

> It is a distraction from your own death which is a momentous occasion. People will be concerned about getting my organs, not me or my death.

2. Mutilation. Many respondents were concerned about mutilation of the body. Organ removal was perceived as somehow unnatural. Some believed that you would have to be cremated or would appear disfigured in the coffin. Several respondents confessed that they knew rationally that this was not the case, but were emotionally repelled by the idea.

> I'm concerned about how my friends and family would feel. You have to respect your family. They want an open coffin and it would have to be closed.
>
> I'd sign, but my wife and children object. The children don't like to see daddy cut up.
>
> How do you look afterwards? I know it is irrational - your eyes are closed, of course...it's an emotional fear I have.

3. Fatalism. A surprisingly large number of respondents had a very fatalistic view of any preparation for their own death, including organ donation.

> Once I sign it, I'm dead.
>
> It's very final to sign it and admit you're going to die. You will probably die immediately if you sign it.

4. Religion. People of the orthodox Jewish faith hold religious beliefs that prohibit the mutilation of the body after death. This is a problem in terms of both organ donation and autopsies. All but one Jewish respondent believed that organ donation was forbidden by orthodox beliefs. One, however, claimed that mutilation of the body was acceptalbe if it was for the purpose of saving another life. In any case, individuals of the Jewish faith are not offended by appeals for organ donation.

Although no respondents were Jehovah's Witnesses, most assumed that this faith would prohibit organ donation beacause they prohibit blood transfusions. Organ donation was not perceived to be a problem for any other religion.

5. Age: too old or too young. Most of the parents we interviewed (40-60 years) felt that they were too old to donate organs. They approved of their children donating and all claimed they would respect the wishes of their children. However, they did not sign their own donor cards.

> I think they are more interested in young people, not old organs (age 50).
>
> I'm too old to be of use to anyone.

Others excused themselves on the grounds that their generation was not comfortable with the whole idea of donating organs.

> Young people grew up with this...we have to get used to the idea.
>
> I think the people who have signed are young teenagers. My daughter and all of her friends have signed. We're older. We're aware of our own mortality. When you're 18, you're going to live forever. Us old people, over 30, die.

But two very young respondents stated:

> I don't like thinking about it. It never occurs to me that I'll die. It is such a long time away for me.

6. "I just never thought about it". Many non-donors stated that they hadn't signed a donor card because it just never occurred to them. Several volunteered, at the end of our discussions, that they thought they would sign now that it had been brought to their attention.

> Now that I've thought about it, I think I'll sign it. Why not? It is a very good idea.
>
> I'm going to discuss this with my wife. If she agrees, I think we should sign it.

7. Minority views. A small group of respondents expressed some cynicism and distrust of physicians.

> Will they try less hard to save you? It gives them a reason to let you die. I don't want a doctor who is trying to keep me alive even thinking about this.

This was definitely a minority view, and respondents expresssing such views were attacked by the majority who supported a more sympathetic stance towards the medical profession.

Two respondents took a fairly cynical view of transplants and the quality of life that would be afforded to a recipient.

> What's the point? It is not that beneficial. That kid with the liver...all the other organs are damaged already....you only live a few years.
>
> When a kid is so sick, you have to worry about the quality of life possible. Why keep the kid alive when life will be so awful?

A number of older respondents had experienced requests for autopsies following the death of relatives. Interestingly, none had been asked to donate organs. Experiences with autopsies were universally negative. Although they differentiated organ donations as more useful to other people than an autopsy, their experiences coloured their expectations of what might happen if they agreed to organ donation.

> No one knew where she was in the hospital. We were very disappointed in the way it was handled.
>
> We had to wait twelve hours and no one told us anything.

What respondents wanted was timely and truthful information about the whereabouts of the deceased, the procedures that were being carried out, and an estimate of the time necessary to complete the procedures. They wanted to know that someone was being respectful and concerned about the body and they wanted to know who to contact, who was in charge of the procedures.

Donating for Research is a Problem

Only one donor had also signed to donate his body to a school of anatomy for medical education or research. All other respondents, both donors and non-donors, were opposed to donating the whole body for research purposes.

> The family needs to bury the dead, see a physical burial. The family needs a funeral and the recognition of death.
>
> I'll only sign if it goes to someone else to help them. Not for research at all. Can I cross that part out?

The primary motivation for donating organs is to help another person to live. The awareness that one's organs might be used for other purposes is a disincentive. The general public does not understand that research contributes, in the long term, to saving lives.

Is the donor card legal? The role of the next of kin

In every group, donors, non-donors, and parents, an argument ensued about the legality of the organ donor card. In each group, respondents spontaneously took out their wallets to examine the donor card in detail.

This examination failed to resolve the question of the legality of their signature. About half the respondents believed that their signature on the donor card represented a legal document and that the next of kin had no say in the matter. Half the respondents, however, thought that the next of kin did have some say, but were confused about what would happen in a case of conflict.

Regardless of their beliefs of the legality of their signature or the rights of the next of kin, all respondents insisted that the donor card should be treated as a legal document not to be overridden by the next of kin.

Three reasons were advanced for this attitude. First, that the whole point of the driver's licence card is to relieve grieving relatives of the decision at a time of great stress.

> Signing is a good idea -- it relieves the next of kin of a decision they are in no shape to make. It is not on your mind if you are the survivor. You're not very rational.

Second, giving the card the status of a legal document facilitates the transplanting of organs quickly.

> It's too bad if the next of kin are involved. It screws up the system...what if they are out of town?

The third reason for making the card a legal document is that one should be master of one's own body, even after death. Donors were outraged to think that anyone could countermand their expressed wishes.

> If I've signed, that's a contract with me. I'm really sorry to hear the next of kin has anything to say about it.
>
> If the next of kin has a say, what's the use of the donor card? How can I insist that they do it? How come they get a say in this? It's my organs.

Non-donors agreed that the signed donor card should represent a legal document.

> The person decides himself. No one else should have the burden of the decision. I'd be offended if I were the relative...it's an added stress for me, especially if we hadn't discussed it.

In sum, respondents were confused about the legality of their signature. However, donors and non-donors firmly believe that the next of kin should not be able to countermand a signed organ donor card. Donors were outraged that their relatives might be able to prevent their donation. Non-donors were comforted by the fact that a legal signature relieved the relatives of the burden of decision.

Family communications

The majority of donors had informed their spouse of their decision. The few who had discussed the issue with their spouse felt that married couples would instinctively know a spouse's wishes.

> My husband signed his card. I don't know if he knows I signed. I never thought to ask. It's just automatic to sign it when I get my licence.
>
> Even if you never dicussed it directly, you'd have some idea because you know them. Use your instincts.

Among parents of adult children, only about one-third knew their children's wishes, and some only because a family discussion was provoked by their invitation to the focus group. All parents, including those who were non-donors themselves, stated that they would honour their children's wishes. Some did not want to be involved in the decision at all.

> They shouldn't ask me. She (daughter) signed the card and I'll honour it. I don't want to know all the procedures they'll be doing.

> It's none of our business what the children have done. It's their decision. But it's nice to know so you're not surprised.

In sum, all respondents stated that they would honour the wishes of a spouse or an adult child. In most cases, spouses are aware of each other's decision and when the subject has not been discussed directly, feel that they instinctively know what the other would want. However, only about one-third of parents of adult children were aware of their children's views on organ donation or whether their children had signed an organ donor card. All parents, donors and non-donors, stated that they would honour their children's wishes.

Donating of minor children

Donors felt very positively about donating organs of a minor child who died. Non-donors who disqualified themselves on the basis of age also felt that they would donate a child's organs.

> I certainly could donate my kids organs. If you're in the Hospital for Sick Children, you see other kids who need all sorts of things. It's very real when you're so close to it.
>
> At least the death is benefitting another child. A little bit of your chid is living on. It reduces the absurd element of a child's death. At a time like that, I think it would be a comfort.

Who is a suitable donor?

All respondents believed that young, healthy, accident victims were the most desirable and suitable donors. Non-donors tended to disqualify people who are ill, diseased, or middle-aged.

> I'm too old (45 years). I have body breakdown by now. They want young, healthy children and teenagers. They're considered prime donors. You'd never even be asked if you die of an illness or disease. They don't take cancer patients.

> My organs are no good anyway. I've got poor eyesight, heart problems, have a kidney ailment, and smoke.

Donors recognized that disease or age can be a disqualifier sometimes, but believe that physicians can be relied upon to make the decision based on extensive testing.

> Let the doctors decide. They do a ton of tests. They do them even when you give blood. You may have a disease you don't know about. They'll check you all out.

Living donations

Most respondents thought they would make a living donation to a person in their immediate family, but since they had no information on the risks involved, such "goodwill" responses must be treated with caution.

> Blood is thicker than water. I can't imagine saying no. Who could object? You'd have to be extremely cold or selfish.

Buying and selling organs

Respondents were universally opposed to the idea of paying for organs. Some noted that our culture is different from the United States in this regard. We have medicare and we provide blood for transfusion free of charge.

> It's despicable, cruel, stupid, and ignorant.

> Not everybody can afford it. It should be available regardless of funds.

Recognition for donors

All respondents, both donors and non-donors, greeted this idea with a resounding "no". Organ donation is considered a private, personal decision, not for broadcast.

> You don't do it for publicity. If that's why, forget it.
>
> It gives me the willies that someone might donate to get recognition -- it's like paying for blood.
>
> No, it's a personal decision and a private thing.

THE ORGAN DONOR SYSTEM NEEDS TO BE IMPROVED

When respondents considered what should actually happen if a transplant were to take place, they concluded that the system probably doesn't work very well. There are problems with identifying donors and with the response of the health care system.

The donor card is inadequate

The driver's licence donor card was seen as a good way to raise the consciousness of most people, but inadequate to permit action at the time of death.

> The licence is a good system. It raises your consciousness. I never knew what to do before. It's very convenient.

But respondents realized that in many cases a licence would not be available at the time of death. Even if it were available, emergency personnel would be preoccupied with doing their jobs and not looking for an organ donor card. Most respondents had simply imagined that a system was in place where donor information was recorded. As they talked, they realized that is probably not the case.

A donor identification system is important

Donors and non-donors felt strongly that a central donor identification system should be in place. Donors reasoned that the next of kin might not be available in time to give permission for organ removal. Donors and non-donors believed that a central donor record would eliminate the involvement of the next of kin. Donors felt this would protect their personal decision and ensure it could not be counteracted by relatives. Non-donors wanted to spare relatives from the burden of such a decision.

Many central record systems were discussed and rejected as unworkable: OHIP, social insurance, hospital identification cards, insurance companies, and the federal income tax system. A coded Visa card was seriously considered as a large audience could be reached through this system. But in the end, the Ministry of Transport computer was the system of choice. The donor card is already attached to the driver's licence and the Transport computer system is accessible to police and hospital personnel 24 hours a day.

The health care system is disorganized

As respondents considered what would actually happen should a close relative die, they expressed a lack of confidence in hospital personnel as far as organ donation was concerned.

> I'm not sure the medical profession asks the question. None of us have ever been asked. It would be difficult for them, I guess, to ask the family.
>
> It sounds as if you should educate the doctors. No one here has ever been asked (to donate organs of next of kin).The hospital staff can't look in your purse, you know -- they won't find your licence. If the doctor doesn't even ask, he is missing a lot of opportunities.

Respondents concluded that someone has to ask. Organ donation would not be on your mind when a relative died. Most respondents thought that a physician was the appropriate person to ask for the donation. However, about one-third stated that any professional person who had been involved with them during the course of treatment would be quite acceptable.

> It should be a professional person, a doctor or it could be a social worker. Doctors are best. They know what they're doing and are relating to you anyway about the condition of your relative.
>
> It doesn't matter who asks...you probably won't care. It would be nice to have someone you've seen before. There are usually so many people around in a crisis situation. It could be a nurse...whoever has been dealing with you.

The European System

Respondents were told of the system in many European countries whereby it is natural to remove organs upon death. One signs a card to prohibit removal. Attitudes to this system were mixed. The majority thought this was a good system that avoided a lot of problems but that it would not be possible to introduce the system here because of our different values about individual and state rights.

> You'd never get away with it here. The state owns the body. Here we have a culture of individual rights. It's like saying my body belongs to the state. This body belongs to me.
>
> It's a good system. It gets around a lot of us here who've just never thought of it.
>
> I don't want to sign...it's like signing my life away. But I'd rather we had the European system. Then they'd do it, which is okay with me, but I don't want to sign.

PUBLICITY IS NEEDED

During our discussions, respondents became increasingly aware of their lack of knowledge about organ transplants. All groups spontaneously discussed the need for publicity about organ donation. Discussion centred on three aspects of a publicity campaign: awareness, information, confrontation.

Awareness

Respondents emphasized the need for constant, ongoing publicity that would make organ donation a routine, natural thing to do. Many respondents referred to the continuous campaign for blood donors as the model for a good publicity program. They proposed five features for an awareness campaign.

1. An ongoing campaign makes organ donation routine. Respondents felt strongly that great strides could be made if organ donation were perceived as a common, natural thing to do, in much the same way as blood donation is now perceived.

> The ads should make it all commonplace so that no one is shocked or offended when asked.

> I like the "stars" on T.V., but they should be on the buses and subways...every day..not just a flash here and there.

2. Tell us success stories. The primary motivation for organ donation is to help someone else. Respondents want to know that it really does help. Donors and non-donors want to hear success stories.

> They don't publicize the successful cases enough. People don't know if it's experimental or long lasting. We hear about the experiments, but not the real successes.
>
> I wonder what the success rate is...they don't talk much about that.

3. Follow up highly publicized cases. Respondents do relate to highly publicized, unusual cases, covered by the media. They resent the fact that the stories are incomplete.

> It's like missing the last episode of a serial.
>
> Tell us what happens. Look how everyone was watching and hoping for Barney Clarke.

People want to know the outcomes, the end of these stories. They are also interested in unexpected impacts, e.g., a number of children were helped.

4. Tell us the need. Respondents have no idea of the need for organs for transplant. They frequently compared this lack of information with the continuing update they get through the media for the need for blood.

> Make people aware that organs are needed constantly. I just never thought of it. They publicize the need for blood when there is a shortage.

5. Draw attention to the driver's licence donor card. Respondents felt that many people were not aware of the driver's licence donor card and were not encouraged to attend to it.

> The licence is a good system, but it's easy to miss. It's the same colour and in fine print.
>
> Advertise the fact it's on your driver's licence. People don't even see it.

Information

Respondents were acutely aware of their lack of information about organ transplants. They felt that some of the information they wanted could not be conveyed in an advertising campaign. Information campaigns should be designed to fight the fear of the unknown, to respond to some of the myths and questions in people's minds. Chief among these are: declaration of death, hastiness of organ removal, the status of the body following organ removal, and suitablility of donors, especially re: age. Respondents proposed that inserts with the driver's licence renewal and television dramas were good vehicles for information.

Confrontation

Respondents emphasized that following awareness and information campaigns, they had to be confronted with an action decision. They were critical of a current media appeal in this regard and felt that it was a lost opportunity.

> You have to be conditioned to make the decision. That's awareness. You only make the decision when you are confronted -- when someone asks you.

It's too bad (the curernt media campaign) is all focused on one kid. What about all the other kids? And there was nothing I could do. They should've said "sign your card" at the end of the appeal.

Respondents had very high awareness of ongoing, health-related campaigns. Many referred to them in discussion and quoted relevant slogans with ease. Campaigns related to blood donation, alcohol abuse, and mental health had very high recall. Respondents approved of using feature personalities and children in advertising. They emphasized that these should be well-known entertainers, sports personalities, or media stars, and not political figures.

> Use people who are "idols", especially for the young people who are the best organ donors.
>
> Use kids, Unicef does and Jerry Lewis. How can you resist? Children get to people.

Summary

A growing proportion of the public believe that organ transplants are successful and that organ donation is a way of helping someone else. Potential donors would prefer a legally recognized donor card that cannot be countermanded by the next of kin.

Major reasons for not signing an organ donor card are: hastiness of organ removal; mutiliation; fatalism or superstition; religion; age; "I just never thought of it".

Respondents recommended a more aggressive approach by hospital professionals seeking consent for donations and more continuing publicity about the need for organs.

PROFESSIONAL AND SYSTEM BARRIERS TO ORGAN DONATION

The role of the health care system in facilitating organ donations has been a major theme of the Task Force on Kidney Donations. Our study of public attitudes to organ donation indicated that system factors were perceived to be a major barrier. Those who had signed a donor card were angry that their "contract" might not be fulfilled when hospital staff did not initiate the donation process.

The Task Force conducted a survey of relevant hospital personnel to identify professional and system barriers to organ donation. The in-depth study in three hospitals was designed to provide a richer interpretation of the quantitative survey data and to test some potential solutions to perceived barriers.

RESPONDENTS

Personal interviews were conducted with 27 neurosurgeons, neurologists, other medical specialists with a potential interest in organ donation, residents, ICU nurses, clergy, and administrators in three types of hospitals. The hospitals were chosen by the Task Force to represent different perspectives on kidney donations. Hospital staff volunteered for the interviews.

One hospital is an acute or primary care hospital providing regional dialysis service in a small city. The hospital does not receive trauma cases and the only neurosurgeon in the county works in a nearby hospital. Patients in the ICU tend to be elderly transfers from nursing homes and critical dialysis cases, neither suitable to be kidney donors. The nearest teaching hospital is some 100 miles away. The staff had virtually no experience with organ donation since the patient population does not give rise to many potential donors.

The second hospital is a teaching hospital with a regional dialysis unit. It is resposible for organ retrieval in Eastern Ontario. The hospital is focused on kidney donations; multiple donations are rare. Residents are available on-site during evenings and weekends. Two neurosurgeons and four neurologists are on-staff at the hospital. One is particularly committed to organ donation. The hospital has an "open" ICU where patients with a wide range of diagnoses are cared for by the attending doctor.

The third hospital is the retrieval and transplant centre for Central and Northern Ontario. Trauma cases are received through its emergency department. Potential donors are transferred to the hospital from other centres. Multiple donations are quickly becoming more common. The hospital has a specialized neurological ICU in which staff are highly sensitized to organ donation. All patients are in the care of a neurologist and neurosurgeon. Residents in these specialties staff the ICU nights and weekends. In spite of this, the Task Force estimated that at least 45% of potential kidney donors were not converted into actual donors.

POTENTIAL BARRIERS AT EACH STAGE OF THE DONATION PROCESS

Donor identification

The identification of potential donors depends on characteristics of the hospital, the education of staff, and the supporting procedures that are in place. Barriers at this stage include: the likelihood of the event, lack of knowledge about suitable donors, lack of interest and support from physicians, and lack of confidence about procedures to be followed.

In a primary care hospital, potential donors are rare. The low frequency of donors makes it difficult to keep staff alert to the possibility of a donor patient. The potential for donor identification increases with specialized services. In a closed and specialized neurological ICU, any patient for whom aggressive treatment is not indicated will be identified by the neurosurgeon or the nurse as a potential donor.

Hospital staff are unlikely to raise the possibility of organ donation if they are not educated to recognize a potential donor. In the primary care hospital, knowledge about suitable donors was quite limited. Staff have had no education and virtually no experience with donors. In both tertiary care hospitals, young trauma victims were easily identified. However, most staff admitted that other potential donors probably weren't identified very often.

> If the patient is brain dead, you automatically think of it. But if it is elective surgery and something goes wrong, you don't think of it. Young trauma cases you pick up on fast. Forty or fifty year olds don't trigger you for some reason. (Nurse, ICU)

Nurses are unlikely to consider donor potential unless they are confident of physician support. In contrast, the commitment of medical staff promotes donor identification.

> I think sometimes the doctor on call would just see it as a nuisance call, not a real emergency. (Nurse)
>
> That doctor is really visible around here and follows through. He generates a lot of harvests. (Nurse)

Staff are reluctant to identify a donor if they are not confident about how to proceed. Although staff in a primary care hospital are aware of the M.O.R.E. phone number, standard procedures in the hospital are not clear.

> After the consents are signed, I have no idea what is supposed to happen. I'd just call the supervisor or doctor on call. (Nurse)
>
> It happens so seldom here that people don't know what to do. There is no system. (Clergy)

In contrast, transplants centres have clear, written procedures that inspire confidence in the staff.

> Here, I'll show you. Here is all the stuff about brain death. You just do what it says. Here are the consent forms. We all know the M.O.R.E. number but here it is anyway, by the phone. It is all very clear, and all our new staff learn it right away. (Nurse)

Certification of Brain death

Under the Human Tissue Gift Act, 1971, 7(1):

> For the purposes of a post-mortem transplant, the fact of death shall be determined by at least two physicians in accordance with accepted medical practice.

Although Canadian statutes recognize heart death, it is common practice to follow the definition of death recommended by the Canadian Law Reform Commission. It is as follows:

> A person is dead when an irreversible cessation of all that person's brain functions has occurred. The cessation of brain functions can be determined by the prolonged absence of spontaneous cardiac and respiratory functions.
>
> When the determination of the absence of cardiac and respiratory functions is made impossible by the use of artificial means of support, the cessation of brain functions may be determined by any means recognized by the ordinary standards of current medical practice.

Barriers related to the certification of brain death include: lack of agreement about the minimum necessary tests required, the availability and training of physicians, lack of technicial support when necessary, legal responsibillity, and responsibility for maintaining the donor.

No one argues with the definition of brain death. However, there are many arguments among neurologists and neurosurgeons about the minimum essential tests required to establish brain death.

> We use serial EEG's here. Two 30 minute recordings 24 hours apart. (Neurologist)
>
> Two EEG's are no longer the way you do it. It varies now. You can do a variety of tests depending on the patient's status and how much is known about the patient. (Intensivist)

Aside from pure efficiency, neurological specialists believe that simplifying and clarifying the procedures for establishing brain death will make it easier for a wide range of medical specialists to share the burden of the procedure. This is an important consideration because of the small number of neurologists and neurosurgeons available.

When certification requires a neurologist or a neurosurgeon to be one of two physicians involved, it places an enormous burden on a few people. Furthermore, these specialists are concentrated in major centres with teaching hospitals. Almost every neurologist or neurosurgeon we spoke to resents their role in the process. This is not because they are opposed to organ donation; on the contrary they support the idea. It is because of the very real physical and emotional strains involved in the process. It is a thankless and unrewarding task. It costs them dearly in terms of time and stress, but provides no positive rewards in terms of thanks, monetary compensation or work satisfaction.

> We do it for somebody else. It is an inconvenience. I'm busy enough. It is not a role I choose and I wish I didn't have it. (Neurosurgeon)

It is easy to resent the retrieval and transplant teams. Many neurological specialists perceive that while they do their work in the middle of the night, the urologists and nephrologists work during regular hours and get all the thanks.

> There are really only two of us who know the whole sequence. It can take one-and-a-half days from beginning to end. It is hard emotionally and physically. I hate the whole business. It is more trying than a whole day in the operating room.
>
> It means I'm on call 24 hours a day every day of the year. I just refuse. I'm the guy who gets up in the middle of the night so they (retrieval team) can work during the day. (Neurosurgeon)

If the criteria for brain death were simplified and more physicians were trained, neurological specialists believe most physicians could handle the procedure.

> Review the criteria with the aim of simplifying it. Teach other physicians to do the declarations. (Neurologist)
>
> Simplify the brain death criteria. Any internist or surgeon could do it or a senior resident in neurology. Most physicians are entirely capable of handling it with a little experience. (Neurologist)

In a few cases, EEG's or CT scans are necessary to diagnose brain death. Even in a larger centre, the technical staff are not available evenings and weekends to carry out these tests.

> Sometimes you do need an EEG. There is no budget to do them after 5:00 p.m. or on weekends. So you maintain the patient at great expense for several days. The CT scan is now available for emergencies. You can have that done. It is much more expensive, of course. (Neurologist)

The concept of brain death has been widely accepted and is not considered a barrier by neurosurgeons and neurologists. However, legal considerations are part of the reason why many other physicians do not wish to become involved with the certification of brain death.

> Once the organ is donated, there is no recourse. A year later, the relatives will say you didn't explain it well enough and will sue you. It will happen sooner or later. (Surgeon)

As far as we can ascertain, there have been no legal challenges to the certification of brain death in Canada. But establishing brain death as the legal definition of death would encourage more physicians to assume responsibility for diagnosis.

Responsibility for the maintenance of the donor is not always clear. Often, it falls to the physician who certifies brain death. A physician may be reluctant to certify brain death if he believes he will then have the additional responsibility for maintaining the donor. This problem is discussed in detail in the section on donor maintenance.

Families

There are two critical points of contact with the donor families. The first is to inform the family that the patient is brain dead. The second is to seek consent for organ donation. Underlying the whole process is the provision of emotional support and information to the family.

There are potential barriers at both primary points of contact. The first potential barrier occurs when the two messages -- the patient is dead and organ donation is possible -- are confused. The order of events is critical.

> You lose kidneys because of inexperienced people rushing in and confusing the family. Transplantation should not be mentioned until after brain death is declared. Nurses are the worst and interns and residents. They mention it too early. Then the family is all confused. The worst thing is when people believe you will take the kidneys and then the patient will die. I won't accept it. They must understand that the patient is dead first. (Neurosurgeon)

Experience builds confidence when seeking a donation. Every respondent who is experienced in talking with families about organ donation felt positively about the experience. None would hesitate to do it again.

> This is not difficult at all. Usually, we just give lots of bad news. This is so positive. You usually get very quick answers from people. People do know what they want. (Resident)

Those who had not had the experience of talking with a donor's family were somewhat apprehensive. They expect most people to say no. On the other hand, experienced staff believe that asking for an organ is much easier and more rewarding than asking for a post-mortem, something they do routinely. They expect most families to consent to donation.

> If I knew the patient's wishes or if I knew the patient would die in a few days and the family was prepared...I'd feel comfortable mentioning donation. But most of our deaths are sudden and unexpected. We're very busy with the patient and you don't think of it at the time. The family is in shock. I'd feel very uncomfortable mentioning it. (Inexperienced Nurse)

> We decide to treat or not treat. We sometimes have to accept the fact that there is nothing more we can do...and so does the family. At those times, donation can make them feel hopeful. Something good will come of this tragedy. (Experienced Nurse)

Experienced nurses and physicians rely on their intense relationship with the family to sense a patient's or a family's wishes regarding organ donation.

> Usually, you don't know the patient's wishes, but you get a sense of what the patient would have wanted from listening to the family talk. I always ask. I usually get a yes. (Nurse)

Inexperienced staff felt they would be more confident if they knew a patient's wishes in advance. They felt that organ donor cards should be legally binding or that a central record of a patient's wishes would solve the problem. But most disagreed. Experienced staff believed that nothing can supercede the wishes of the family.

> A central record wouldn't help. You just have to ask. There is no escaping it. We ask for autopsies..this (donation) does more good for the family. I don't know why we're so squeamish. Even if it were recorded centrally, you'd never do it without the relatives' consent. (Intensivist)

Donors are lost when physicians are not available.

> You lose them because there are not enough physicians who will be responsible for declaring brain death and I run out of physical and mental energy. You lose them because when I'm exhausted and on my day off, I'm not compensated for the extra work. I just can't be on call all the time. (Neurosurgeon)

Residents, alone on evenings and weekends, cannot always find the time necessary to discuss matters with the family.

> I can't look after 15 sick patients alone and control what goes on with the family -- all their contacts with the clergy, nurses, etc. You need someone to come in and help. (Resident)

> The attending is not usually notified about a death -- they're only called if we need advice on care. It is unpleasant for them -- they usually don't deal with the family anyway. Some think this is just one more thing dragging it out and they don't want to deal with it, especially at night. (Resident)

Each respondent was quite clear about his/her role with the family. However, within each hospital, there was not agreement about roles. The question of who deals with the donor family and when may be resolved differently in each type of hospital. But it needs to be resolved and the decision made clear to all staff. Most neurologists and neurosurgeons personally inform the family of brain death and discuss it with them. A few, however, prefer to see themselves as consultants to the attending physician and it is the attending who talks to the family. Respondents agreed that whoever knew the family best should ask for the consent for organ donation.

> The person taking care of the patient should ask. Not a stranger. We usually have a little discussion about where the family is at and who is the best person to ask. (Nurse)

Several respondents emphasized the importance of keeping the family informed and supported after consent was obtained.

> It is important to tell them (the family) just what to do and what the timing is. We give them the resident's phone number to use so they can talk later. (Nurse)

Maintaining the donor

Three potential barriers are related to the maintenance of the donor patient: responsibility for the patient, understanding and cooperation from the retrieval team, and clearer guidelines re: maintenance standards.

Physicians are accustomed to assuming that their responsibility ends when the patient dies. It is not always clear who is responsible for the maintenance of a donor patient. The attending physician is not usually informed of the death, nor is he/she available or trained to manage the patient. A resident alone sometimes does not have the time or experience to manage the pateint. An on-call physician is not knowledgeable about maintenance and does not consider it his responsibility. Often, the responsibility falls to the neurological specialists diagnosing brain death. This is a responsibility they do not want.

> Making the decision (about brain death) is not a major problem. It is after that that you are in trouble. (Neurosurgeon)

> Usually, the attending is not even notified immediately when the patient dies. If we're really busy on the unit here, we count on the neurosurgeon to be responsible for maintenance orders. That is especially true nights and weekends when I'm alone and the intensivist is not here. You just can't do everything sometimes. (Resident, ICU)

Each hospital needs to decide who will assume responsibility for maintaining a patient, especially during nights and weekends when few staff are available. In hositals where a resident is in charge, arrangements for emergency medical support need to be in place. Physicians called to certify brain death should not have to fear being involved in maintenance activities as well.

Nurses and physicians responsible for maintenance of the donor patient feel that urologists on the retrieval team don't always appreciate maintenance problems.

> They take it for granted. They take their time; they don't get up in the middle of the night. Everyone jumps for them. (Neurosurgeon)
>
> You don't just have all the time in the world. Some physicians don't realize that the patients are not stable when they're brian dead. (Nurse)

Some of the difficulties in this area have to do with poor communications. Those involved in maintenance do not know why the harvest is delayed. Their work is becoming more difficult and the family is anxious. Is the team unavailable? Do they know that the patient is unstable? Is the O.R.unavailable? How long will it be? Better communication about what is happening and why would help the maintenance team and the family to cope with necessary delays.

Although M.O.R.E. guidelines are very helpful, experienced medical staff claim that, in practice, there seems to be a much wider range of acceptable procedures than are written in the general guidelines. There seems to be a need for more elaborate guidelines and more expert guidance with specific patients. This is especially the case when the patient becomes unstable.

> There is often a cafuffle over the care of the donor. The M.O.R.E. book isn't always accurate. We need a range of acceptability for systolic pressure, fluids, which drugs are acceptable, etc. We need clearer, more elaborate maintenance rules. (Nurse)
>
> The chart may say do not resusitate, but you might have to maintain the patient. The guidelines are very vague. (Resident)

EMOTIONAL FACTORS

So far, we have focused on professional and procedural barriers to organ donations. But the death of a patient and the donation of organs are emotional events for both the family and the medical staff. This aspect of the process, neglected in medical education programs, is critical to the consent for donation and is more important to the medical staff than is usually recognized.

The main sources of emotional support for the family are nurses and clergy. Clergy become involved for a variety of reasons -- promoting organ donation, protecting the rights of the family, and caring for the patient, the family, and medical staff.

> It is the only good thing that can come from a traumatic MVA. We have a large dialysis unit and long waiting list. I've persuaded people many times. It's my personal thing. People tell me later it is the only good thing that happened for them. I believe that it is right. I have no hesitation in using my influence. (Clergy)
>
> I become involved when people express a concern from a religious point of view. Many people are unsure. They're not religious people, but when the chips are down ... I sat with a father after two doctors had asked for the kidneys of his 8 year old. Finally, he said 'Is it right?' What he wanted to know was whether his child could get to heaven without his kidneys. (Clergy)
>
> My approach is 'caring' for the patient, the person. Ethical concerns, especially about a living donation. It must be a voluntary giving of self. I am an absolutist for patient rights. The ethics of informed consent and free choice are my concern. (Clergy)

Experienced clergy and nurses understand the importance of working in conjunction with the physician who always has the lead role.

> You shouldn't broach the subject (of donation) when the patient is still alive. They may doubt you're trying to keep him alive any more. (Clergy)
>
> The doctor has to answer the family's questions, especially about brain death when the person still looks alive. But certainly be there with them. (Clergy)

Professional respondents identified two major sources of emotional stress--explaining brain death to a family and attempting to fulfill conflicting roles. For young doctors, there is the additional stress of learning to cope with the death of a patient.

Usually, the neurological specialist declaring brain death has no relationship to the patient or the family. He fulfills a specific, technical function -- testing for brain death. The neurological specialist has to deal with a highly emotional event in total isolation from any meaningful relationship, past or future.

> We tell the family the bad news. We have no relationship with the family. It leaves us hanging in the air while someone else does the consoling. If we do some consoling, it helps us. We're the ogres ... (Neurosurgeon)

Some neurological specialists, like the one quoted above, are more comfortable when they can become emotionally involved, even briefly, with the family. Others appreciate and share the emotional comfort provided to the family by clergy who accompany the physician while he explains brain death. Each physician should have the opportunity to specify what makes him/her more comfortable and should be able to count on the support he/she needs to fulfill this difficult role.

Physicians, and sometimes nurses, are expected to fulfill two conflicting roles simultaneously. On the one hand, they are required to perform highly technical, scientific tasks with considerable expertise, e.g., patient care in the ICU, testing for brain death, etc. On the other hand, they are expected to deal with the feelings of the family and their own feelings around the death of the patient. Donors are lost because it is humanly impossible to do both things well at the same time. Staff shortages sometimes demand both.

> If you're busy with physical things, you can turn off the ugly, unpleasant stuff, but the family needs your feelings. It is hard to switch around quickly. It is painful to deal with the family because your feelings side has to surface. (Nurse)

> Much of what we do is ugly and unpleasant. You do it by shutting down your feelings. With all the goodwill in the world, you just can't turn them on instantly in order to deal with the donor family. You're all alone on the ICU. There is no one to take over so you can switch gears. (Senior Resident)

Learning to handle the psycho-social aspects of the process -- relating to the family and dealing with personal feelings -- requires good role models and opportunities to practice appropriate behaviours.

> In medical school we're taught the theoretical criteria for brain death. In neurosurgery training, we get practical learning. But the whole psycho-social thing -- the family relationships -- are never mentioned in medical school. (Resident)
>
> You learn by doing. We have good models. Neurosurgeons teach us. The first time, it's usually in the middle of the night and you really learn on your feet. You watch, help, listen, and learn. (Resident)

Learning about yourself requires the support of colleagues and mentors.

> Doctors are 'expected to cope' as a training goal. Some doctors feel they have to do this all alone. Nurses have a role in soothing and supporting the doctor and following up with the family. Young, green doctors see death as a failure. Experienced nurses need to help them with coping mechanisms. (Nurse)

Sources of emotional support for professional staff are diffuse.

> In trauma cases, the family has only time to relate to one person. The clery are great at helping the family understand. No white coats and no medical involvement. They treat us (physicians) like human beings too. (Neurosurgeons)
>
> Our staff have trouble sometimes with the process of harvesting. I run voluntary support groups for them. (Clergy)

Major sources of support for professional staff include M.O.R.E., committed senior medical staff, public acceptance of organ donation, and experience with the process.

The major source of support, spontaneously mentioned by many respondents, is the M.O.R.E. program. Respondents know that M.O.R.E. can be counted on to guide them through the most difficult situations. But, above all, respondents appreciate the feedback from M.O.R.E. concerning the outcome of the organ donation. Two nurses referred to these notes as "love notes from M.O.R.E."

> One of those notes could make you into a real crusader. It makes you feel so worthwhile. (Nurse)

> They (M.O.R.E.) are so wonderful. They were delighted to hear from me on a Sunday night. They held my hand through it all. The feedback later is very important. It makes the whole experience more real and tangible. Do they send a letter to the family too? I hope so. (Nurse)

Senior medical staff who are committed to organ donation make hospital staff continually aware of the potential for donations. Their very presence creates a culture of acceptance for the process.

> That doctor is really visible around here and follows through. He generates a lot of harvests. (Nurse)

> You feel like you're letting him down personally if you miss an opportunity for a donation. (Physician)

Lack of this support from physicians seriously inhibits the process.

> I'm not sure the doctors support it. I'd be scared to start the process because there's not enough back-up. They (doctors) may think it is just more work. (Nurse)

Support also comes from the public. As organ donation becomes more accepted, and as more families initiate organ donation, hospital staff become more comfortable seeking consent.

> More and more people are saying that they filled out the card or they've talked about it. It won't seem so strange to them. (Nurse)

> It is easier to ask people when you know that they know something about it. It won't seem so strange to them. (Nurse)

Participation builds commitment. Respondents who had participated in obtaining an organ were very positive about the process, even if they complained about specific aspects of the process and even if they occasionally failed to get consent.

> It is hard not to think of it once you've seen what happens. It is so positive and people are so grateful. It is hard to stop asking. (Nurse)

> Sometimes maintenance is awful. You are prolonging death. You really want it to end and you start to wonder ... but then you realize that you're giving life to someone. It is so rewarding. It is such a positive thing. (Resident)

> I've had people say no lots of times. But I can't stop asking. Sometimes you're really making a lot of work for yourself, but I just feel I have to do it. We're talking about a life ... (Physician)

EMERGING BARRIERS TO ORGAN DONATION

Two emerging issues were identified -- the handling of multiple donations and compensation. Currently, neither issue constitutes a barrier to organ donation. However, respondents believe that if a more aggressive organ donation program is mounted, these issues could be significant.

Experiences with multiple donations have been mostly negative. While the procedure for kidney donation is well documented, the procedure for other organs is not clear at all.

> We had one last year. No one wanted anything but the kidneys. Try to explain that to a family. The logistics of livers are ridiculous. We had five centres in M.O.R.E. and the United STates and none of them know what to do. They said we'll come, we won't come, all night. (Intensivist)

> Multiples can take forever. Once we had extra blood typing for a heart going to the United States; we were waiting for a liver retrieval team from London; everyone was lining up for the O.R.; and the family was calling me about the funeral. The process for multiple donations needs much better organization. (Nurse)

At one hospital, where multiple donations are becoming common, the complexity of the process can be overwhelming.

> You can get the feeling the vultures are descending when all sorts of doctors start inspecting the patient. Then it takes forever to get all the different retrieval teams organized in the O.R. Maintenance can get really tricky. If they're going to do multiples, they're going to have to get a better system ... some general surgeons or something who are trained to do all the different retrievals. (Nurse)

As public acceptance of organ donation grows, the potential for multiple donation increases. The experiences cited above suggest that it is time to develop better procedures for handling multiple donations.

At present, there is little concern about costs and compensation, and no concern about the availability of beds or an operating room. However, physician compensation and hospital costs could become an issue if a more aggressive organ transplant program is mounted. Physician compensation provides some recompense for doing unrewarding work during unscheduled hours.

> I really want my time off. A little time to myself. However, if I'm hanging around here on a weekend, it would be nice to be able to say 'At least I'm getting paid for this'. (Neurosurgeon)

Although physicians can find fee categories in the OHIP schedule that relate to the specific tasks they perform, some suggested that it would be simpler and more convenient if there were a global fee for the declaration of brain death and for the maintenance of a donor patient.

To date, there is little concern about hospital costs. However, respondents anticipate concerns as organ transplants become more frequent.

> The worst questions are related to transfers from the periphery. If a patient is transferred here dead, they can't charge for a bed. If a patient is a potential donor, but survives, who is paying for the care? The doctors really don't care -- they just say 'give me a bed'. But eventually, if it happens more, the administrators will get upset at this. (Resident)
>
> There should be a fund to draw on for all the related expenses. It should not come from general hospital revenues. It is an unpredictable expense. (Administrator)

SUMMARY

Like the public, the majority of hospital staff support the concept of organ donation. Some practical problems inhibit their full participation. We believe that the improvements suggested in this report will substantially enhance the participation of committed professionals in the organ donation process.

Professional and system barriers to organ donation can be alleviated by: clarifying procedures; providing educational opportunities; providing emotional support for professional staff; maintaining and improving communications and advice strategies; lobbying for the legal recognition of brain death; and improving remuneration systems for the physicians and hospitals.

REVIEW: EMOTIONALLY RELATED DONORS AND RENAL TRANSPLANTATION

Introduction

In the past, unrelated living donors were rarely used in kidney transplantation because the likelihood of success was thought to be no better than that obtained with cadaver donors. This was the accepted practice when the one year cadaveric graft survival was approximately 50%. The perceived risk to the donor, given a likelihood of 50% failure made the donor/recipient risk-benefit ratio unacceptable. Another important factor was the reluctance within the medical profession to submit a healthy individual to surgery from which he could obtain no benefit. Coupled with this was the suspicion that the motivation of such volunteers to donate a kidney was abnormal.

The early, encouraging results of Cyclosporine in preventing rejection projects a cadaveric graft survival exceeding that of the previously expected living related (Haplo identical 75%).[1] We believe that these promising results combined with the ongoing shortage of cadaver kidneys[2] and the increasing demand for donors may awaken interest in considering certain genetically unrelated individuals as acceptable donors. In fact, in the last three years some U.S. centres have reported using living unrelated donors[3,4] and transplants with Papal blessing between priests and nuns have been reported from Italy.[5]

Following is a literature review on genetically unrelated donors and discussion of the norms and ethical considerations which have, so far, governed their use. A statement on the current success rates with Cyclosporine justifies a premise for reconsideration of selected emotionally related individuals as donors. Based on the authors' experience with living related donors[6] the importance of psycho-social screening is also discussed.

Literature Review

In the late 60s and early 70s literature on kidney transplantation contains reference to the genetically unrelated kidney donor.[7,8] Articles related to the legal aspect cite no objections to the use of such donors providing the acceptable code of consents for human experimentation and surgery is followed.[9] Ethical and moral opinions centred on the traditional view that it is medically unethical to mutilate the body of a healthy person if he receives no benefit from the act. Other objections were:

1) The results were no better than with cadaver kidneys.

2) Unrelated persons should not be used because their psychological motivation as volunteers was suspect.[10]

3) The fear of legal consequences that such donors might one day harass the recipient or sue the hospital.

Unrelated donors have been used in relatively few transplant centres in the world. The early experience of two United States Centres, Denver and San Francisco, is well documented. In 1964, Marchioro et al[11] reported on a group of 40 donors, 13 of whom were not genetically related to the recipient and included 3 wives, 9 volunteer convicts and one individual who responded to public appeal. Subsequently the use of prisoners was abandoned on the grounds that such a practice might lead to abuse if precedent was established.[12]

In 1967, Sadler et al (University of California Hospitals, San Francisco), began the only published comprehensive study on living unrelated donors. This five year controlled prospective and retrospective study of 22 unrelated donors cited the graft success rates equal to that of their current cadaver series.[13] In addition, the Californian hospitals group sought opinions on the use of unrelated donors from those transplant centres in the world reporting to the Kidney Registry and also conducted a public opinion poll. In summary their reported findings were:

a) 15 of the 22 donors volunteered donation within 12 hours of hearing of the need.

b) After initial reactions of "you are crazy" all were supported in their decision by family and friends.

c) None of the donors reported feeling coerced by physicians.

d) The surgery and recovery periods were uneventful.

e) All donors reported increased self-esteem and there were no indications of regret.

f) Five years post-donation no psychological or physiological complications were reported.

The medical investigators' decision to seek non-medical opinion on the use of the unrelated donors was prompted by the response to their prepublicaton article from 54 transplant centres. This response expressed a high degree of mistrust for human motivation and repugnance to this donor source. The attitude of repugnance to the use of unrelated donors is commonly cited in the literature;[14] it has not gone unchallenged. Fellner and Schwartz[15] say, "that the reasons for the unrelated donor rejection appear to be unscientific, emotional and prejudicial. Furthermore the decision to bar him appears to have been made somehow by private consensus of the medical teams involved who do not seem to be aware that in doing so they are grossly out of step with public opinion". Evidence now exists to support their thesis and to invalidate previous medical and psychological objections to the use of genetically unrelated donors.

Histo Compatibility Issues

The current rules by which only first degree relatives are used in transplantation was based on the proven relationship between haplotype sharing and graft survival. That is, an HLA identical (2 haplotype sharing) sibling resulted in an 85% graft survival; a single haplotype sibling 65%, parent-child 60% and a non-haplotype sharing or unrelated (cadaveric) in approximately 50% graft survival. The reasoning for rejecting unrelated donors was that the likelihood of success was no greater than if one had a cadaver. Therefore, why not wait for a cadaver? Conversely, an identical sibling bore with it such a high likelihood of success that barring significant clinical or psychological reasons to the contrary, this graft was by far preferred to waiting for a cadaver. The greatest discretion was applied to the single haplotype donor where the benefit appeared to be something in the order of 15% (as compared to some 35% in the identical). In spite of the fact that zero haplotype sharing conferred no benefit as compared to a cadaveric source, the use of zero haplotype sharing sibling donors was, and is, an accepted source of donor kidneys. Therefore, the application of this rationale for exposing a living person to risk, based on a perceived reduced risk to the donor, breaks down in this particular application.

New immunosuppressive therapy such as Cyclosporine has obliterated even these lines of discretion or differentiation between an apparently defensible take of a kidney from a living donor and an indefensible take. Cadaveric transplantation with Cyclosporine now carries with it approximately 80% graft survival[16] and is certainly not distinguishable from the old results obtained with living related donors. Now, there may be, with experience, a proportional improvement in graft survival in the living related and we have little doubt that incremental improvements in graft survival will occur, based on the degree of identity between donor and recipient, but at best this is likely only to be in the region of 5% at each level of haplotype sharing. So, one is no longer able to use the histo-compatibility argument for rejection of living unrelateds. This argument was of course already weakened by the use of zero haplotype sibling donors.

Rigid criteria are currently applied to the selection of a single haplotype donor of a kidney for a healthy patient without preformed antibodies, in view of both of the expected success rate (70%), and the possibility of obtaining a cadaver graft for such a patient. The rigidity of these criteria may, however, be modified in the case of an identical donor for a highly presensitized recipient where the expected success rate is considerably higher (95%) and the chance of a suitable cadaver graft markedly reduced.

Psychological Issues

In turning to psychological issues, the question to be answered concerns the difference or similarity between unrelated and related donor responses. Three studies are available: Sadler's, summarized above on unrelated donors, and two by Simmons who first conducted a controlled study with 230 living related donors 2 years post-transplant[17]. In this group 95% derived psychological benefit in terms of self-worth and expressed positive feelings around donation. The remaining 5% comprised the donors who, after 2 years, harbour negative feelings. Included here are the ambivalent donors; those who scored low on pretransplant happiness and self esteem scales; the black sheep donors; and those who see the recipient experiencing medical complications at 2 years. Simmons followed the same group of donors 5-9 years post-transplant[18]. Most of these donors had maintained positive feelings about donation and demonstrated greater closeness to the recipient than the non-donors. The majority of donors whose kidneys had not survived also maintained positive attitudes, although regret and lower levels of closeness to the recipient were somewhat more common in this group. The related donors showed higher levels of self esteem at 5-9 years than they demonstrated prior to donation and than the control group of non-donors. Such findings together with Sadler's unrelated group encourage us to assume that the responses of the emotionally related individual would be similar.

Societal Issues

The rights and wishes of recipients and donors merit further examination. As early as 1975, Katz and Capron[19] urged the formulation of a definite policy regarding the use of unrelated donors and further suggested that this issue should not be resolved by physicians alone. They ask the question, "Does society have any interest in preventing a person from making a gift of an organ if that creates risk to their own life?" An analogy to consider is that of a husband who enters a burning house to rescue his wife. This act of inherent altruism would be acclaimed by society. Conversely, the husband's failure to attempt the rescue would affront societal expectations and label that individual as cowardly. Donation of a kidney to his wife would be regarded by society as beyond inherent altruism, although the donor nephrectomy performed in a controlled situation would likely place the husband in less danger than entering the burning house.

Nine years later, Dossetor[20], in urging consideration for the use of emotionally related and altruistic donors, addresses the question of who should be the 'gatekeepers'. "No longer is the public prepared to accept only the medical profession's judgement on this sort of issue. In the final analysis I submit it is society which decides". Dossetor echoes the need for the development of policies on the use of unrelated donors.

The Emotionally Related Donor

The International Transplantation Society in 1984 condemned the recent scheme for commercial purchase of organs from living donors as a morally and ethically irresponsible proposal[21]. While in complete concurrence with this statement can we justifiably continue to ignore the voluntary offers of kidneys from those who are emotionally related to the recipient?

We define the emotionally related donor as a spouse, common-law partner or close friend (probably of long standing) with whom the recipient has a stable, healthy and mutually supportive relationship. In pre-Cyclosporine days three such individuals approached this centre to offer kidneys. In the first case a husband and wife, joint employers and long time friends of a 38 year old male recipient, offered to donate. They expressed genuine regret when they were told this was impossible and questioned us closely as to the reasons. They continued to be very supportive to the recipient while a protracted search for a donor among his 13 siblings was undertaken. He eventually received an HLA identical kidney from a sister with an excellent result. In this instance an HLA identical kidney would have been, in any event, the "transplant of choice". Our second example involved the wife of a 35 year old recipient with a strong family history of nephritis, his mother, 2 brothers and nephew all having the disease. The wife repeatedly offered her kidney and requested that, at least, she should be tissue typed. Her request was refused and her husband received a cadaver kidney three months after starting hemodialysis. Now, 3 years later in chronic rejection, he is awaiting a second cadaver kidney. If his wife should again come forward, are we still justified in refusing to tissue type her, especially as there is no chance of a sibling donation? In such cases should the availability of kidneys from other sources such as living related affect the decision?

Issues in the Use of the Emotionally Related Donor

The major issues to be addressed in considering the use of an emotionally related donor are:

1) Informed consent and absence of inducement or coercion.
2) Physical and emotional well-being of the donor.
3) Safeguards against financial penalty for the donor.
4) Societal and medical prejudices.

In the authors' experience with live-related donors, the existence in many cases of free-will informed consent has been questionable. There is frequently subtle or overt pressure brought to bear on a related donor by the family, the recipient or the medical team. At this centre, 3 potential donors have been rejected on grounds of unacceptable family coercion which was revealed at the time of psycho-social assessment. It is more likely that the emotionally related donor would be a true "volunteer". The individual would not be expected to donate, as currently happens in families, and could discuss the possibility with the physician in their own time without experiencing the stress which so often exists when a family is searching for a donor[22].

The physical well-being of any living donor is of prime concern with safeguards being applied to protect him from a life threatening situation or disability. With detailed medical work-up and present high surgical standards, the relative risk of morbidity and mortality to living related donors has been acceptable when the benefit to the recipient is weighed against this[23]. These acceptable risks have borne an unexpected sliding scale relationship to the expected success rate in the recipient.

The individual should also be safeguarded from any financial cost. It is already customary in Canada for the medical and surgical expenses of the living related donor to be charged to the recipient's health insurance. Other hospital charges such as user fees should be waived in order to free an emotionally related donor from any financial burden incurred in the course of donation. A subsistence allowance for the donor's family might also be considered in certain circumstances.

To ensure the emotional well-being of such donors, psycho-social screening is of the utmost importance. In this center's experience with living related donors, a social work evaluation combined with psychological testing has worked well, with the occasional need for psychiatric consultation in cases where psycho-pathology has been identified. In the assessment of the emotionally related donor we advocate such evaluations occurring after tissue typing has established a negative cross-match, but prior to medical work-up. This prevents psychologically unsuitable individuals from being subjected to unnecessary medical procedures. The protocol for social work assessment currently used in this centre addresses the individuals' family situation, education, employment and financial status, motivation and intra-psychic adjustment. The presence of anxiety and conflict in the donor family and its members' attitude to donation is also explored.

Lack of "donation consensus" may not only affect the clinical course of the transplant, but can also be damaging to family relationships[24]. We have a responsibility to diagnose such situations and to intervene offering information and support to the family. In the case of the emotionally related it would also be important to assess the donor/recipient relationship interviewing them jointly in addition to the usual individual donor assessment. Contraindications for donation would be evidence of extreme ambivalence, blackmail, coercion, pathological donor/recipient relationships and, in the case of spouses or common-law partners, presence of severely dysfunctional relationships.

Summary

Published medical and psychological evidence now available strongly supports the widening of donor sources to include the emotionally related donor. Irrespective of the benefit conferred by a living related over an unrelated donor, it now seems indefensible to refuse the donation of a kidney from an emotionally related individual to a recipient who meets the required criteria. An absence of other donor sources, the existence of preformed antibodies or priority on the transplant list all seem to us to be compelling reasons to consider the use of the emotionally related donor. This is especially true when the psycho-social assessment reveals a true volunteer who is likely to derive psychological benefit from the donation and where 'donation consensus' exists within the family.

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ETHICS OF TRANSPLANTATION

C.R. Stiller

Introduction

There have been few areas in medicine where as much attention to ethical considerations has been focused as in the area of transplantation. The idea of declaring a person brain-dead while still maintaining life, the transfer of life-sustaining organ function from one individual to another, the mythical reverence of the heart as the seat of man's soul, and the right of an individual to determine the eventual disposition of his/her body and its parts have all evoked vigorous debate in several disciplines. In addition, the potentially unhealthy motive of self-interest may readily be expressed in this area in which there is such a gross distortion between supply and demand of transplantable organs. Surprisingly, until just recently, the field has been relatively free of major ethical misappropriations and this has largely been due to the fact that the number of individuals involved with decision-making in transplantation has been limited and these individuals have largely been motivated by scientific and charitable directions. However, the rapid expansion of this area requires some guidelines that provide for a practical and efficient system of organ retrieval and distribution while being sensitive to important ethical parameters that should constrain the transplant physician or surgeon.

Definition of Life

In order to obtain a cadaveric organ the donor must be declared dead. Before the onset of transplantation, the definition of brain death was required in order to terminate life support mechanisms in patients who had no functioning brain tissue or hope of recovery. However, this has become a fine science as the need for early declaration of brain death and sustaining of the donor have become requirements for efficient and successful transplantation. The definition of brain death is now well accepted and the criteria for this declaration have become universal. The Human Tissue Gift Act of Ontario (1972) has determined that the declaration of death must be performed by two individual physicians not associated with the transplant team; that is, independent decisions are made in the best interest of the dying patient and not with considerations of the transplant recipient in mind. This procedure is universally accepted and to our knowledge rigidly applied in all hospitals since its performance is documented on the hospital charts and is a prerequisite in order for the donor to be taken into the operating room.

However, the declaration of brain death does pose some rather important ethical considerations operatively within the medical care system. Following declaration the patient is now dead and policies for ensuing procedures involving this corpse/patient are frequently vague and ill-defined. For example, the body cannot occupy a hospital bed for purposes of reimbursement, nor can it be flown by the air ambulance as the rules governing air transportation specifically prohibit the transport of a cadaver. Yet, the management of the brain-dead patient requires a greater attention to life support systems than existed during the previous management of that patient. Each one of the organ functions must be optimized so that heart, liver, kidney, lungs and pancreas will be suitable for retrieval. As well, the attitude of health care personnel to this body, previously an individual that they knew (and now a body with no connotation of human life because death has been declared), provides an emotional dilemma for nurses and physicians.

There are considerable operative problems in categorization of these patients for purposes of transfer to a new intensive care unit. When a potential donor is admitted to a hospital, the transplant physicians and surgeons should not be involved with the care of that patient if he/she is still considered to be alive. Yet, to admit a patient and conduct a number of laboratory investigative procedures regarding donor suitability requires a patient I.D. number which implies that the patient is alive. It is clear, and was evident to members of the Task Force, that a new designation of this state is required. The term 'cadaver' does not adequately define this individual and obviously the term 'patient' is inappropriate. A term such as 'life-supported cadaver' would be appropriate but the regulations surrounding hospital audit for purposes of occupancy, reimbursement, and the use of transportation facilities would have to include this new definition of a life state.

Furthermore, there are well documented incidences in which patients have been referred as potential donors with a diagnosis of probable brain death made in a peripheral centre but, upon examination according to protocol, they were in deep coma and not brain dead. It is therefore a practice of most centres to have a team which confirms brain death. Indeed, the Munich group provides two teams, separate in organization and transportation, that go out to each hospital when a potential donor is identified. The first team consists of neurologists who determine that brain death has occurred prior to the retrieval team being activated. In the Ontario and Canadian context this practice is usually done by transferring the donor into the transplant centre with independent determination of brain death by neurologists occurring there. Although there is no fundamental disagreement as to the definition of life and brain death, on an operative level, clarification and documentation of definitions which impact on the use of our medical facilities are required.

Rights of the Donor

(1) Right to Give:

Traditionally, society has either given the right to the next of kin for the disposal of the body or has remained silent on this issue. In Ontario, this traditional right of the next of kin was altered by the Human Tissue Gift Act in which the individual could determine, prior to death, whether the organs could be used for transplantation. In practice, however, the wishes of the next of kin are always ascertained before the organs are retrieved unless no next of kin are known in which case permission from the coroner is obtained. This "right to give" which was included in the Human Tissue Gift Act applied to both the post-mortem donation of organs and tissues as well as inter-vivos transplantation.

The Task Force, in considering this right to give, examined a number of ways by which such wishes might be recorded. The individual must not only have the right to give but the opportunity to change his/her mind and the most difficult operative problem was determining a method that provided for easy access but which also had the least opportunity for error. Ethically, it is important that such a process safeguard an individual's "right to give" while protecting that same individual's decision not to donate if he/she so chooses. In some jurisdictions the law has allowed removal of organs irrespective of the wishes of the donor in the post-mortem situation. In other jurisdictions a process of presumed consent has occurred in which, if the cadaveric donor did not state any pre-mortem objection to post-mortem organ removal, the physician or surgeon could assume that an objection did not exist and the organs could be taken without reference to the next of kin.

Task Force results indicate that 63% of those individuals polled want their organs used after death but only 26% of these people had recorded this decision. In essence, the majority of individuals would like to donate but do not sign the driver's licence and yet, presumably, if they had strong positive feelings towards donation they would indicate this to their family. Therefore, the majority of relatives, if asked, will agree to the donation of the organs of their brain-dead relative and this procedure should result in 60% to 85% of potential donors becoming actual donors. The conclusion of the Task Force was to encourage a system in which the interests of the donor (recorded or otherwise), the emotional needs of the donor family and the need for increased organ donations would all be protected. The factor limiting the donation rate, as emphasized elsewhere in this report, is the process of seeking consent. If there is an important ethical implication it is that the medical profession is responsible for asking relatives if they would like the organs of their loved ones used and/or asking the relatives if the deceased had indicated whether they wanted their organs used.

With respect to the living donor the right to give is a profound ethical consideration and it was the consensus that altruism is noble and has a right to be expressed. At the same time, important measures to protect the individual who may donate without knowledge as to the possible risk involved and alternatives for the patient such as cadaveric transplantation were considered and form part of the recommendations of the Task Force. However, there was consensus that the physicians' attitude of cynicism with respect to the potential donors' motives was inappropriate since the primary task of the profession is to guide the donor in his/her decision and to make sure that unneccesary psychological or physical damage does not occur while performing this act of altruism.

(2) Right to Direct the Gift:

An important operative problem would arise if a situation developed in which cadaveric donors (pre-mortem) or relatives specifically directed the recovered organs to specific recipients. On the surface, it would seem this option should be the absolute right of a donor. For example, circumstances have occurred in which an individual's relatives have indicated that they have another family member on dialysis and they would like one of the kidneys transported for transplantation into this particular recipient. In that situation it seemed quite appropriate to perform the wishes of those relatives. However, a number of national media appeals have occurred requesting donation of livers for children. Parents of dying children directed such organs to be sent to a particular program for a specific recipient whom they had seen on television. This occurrence raises the spectre that the individual with the greatest access to the media is the one most likely to obtain an organ. However, an additional potential problem involves the establishment of a direct relationship between the relatives of a deceased donor and the recipient family. Post-transplant, there is the possibility of emotional and financial coercion. For this reason the Human Tissue Gift Act precludes the identification of the donor and recipient by physicians. This area requires a great deal of discussion from both the ethical and legal viewpoints and, at present, there is not consensus among the medical profession as to whether a family has the right to direct an organ's destination.

On the other hand, the right of the donor family or the donor to indicate the type of organ/tissue used, for what purpose and presumably in what country or region must be protected. In general, relatives are specifically asked which organs they wish to have used but usually no restriction is placed on the physicians as to where the organ might go in terms of region or country. In some instances, the donor body has to be moved in order to obtain ideal conditions for removal, for example, heart and lungs. In this situation it is clearly the right of the relatives to stipulate conditions by which the body may or may not be moved. Most programs are sensitive to this situation but, as noted elsewhere in this report, many of these operative principles are not recorded in any formal policies and yet clearly they should be.

(3) Reimbursement:

The right to be reimbursed for costs is often neglected and yet reimbursement should clearly occur. In many instances, costs of travel on the part of the family to make a donation, or additional costs in arranging for the body to be transported after donation are not reimbursed because there is no mechanism by which that can occur at the present time. In addition, the costs of the living donor for time off work, recuperation, direct out-of-pocket expenses for transportation and living costs are not reimbursed at the present time. There should not be a cost to the donor and direct payment should not occur from the recipient to the donor. The system pays for the cost of retrieving a cadaveric organ (from $7,000 to $10,000) but has no provision for the costs of living donors. This arrangement is inequitable and has some clear-cut ethical implications if not corrected. Direct payment for organs, other than reimbursement of costs, is thought to raise a spectre of commercialization which is undesirable, unnecessary, and may destroy the system. As the survey by the Living Donor Subcommittee determined, the majority of donors oppose payment and the lack of such in no way has deterred donations.

Rights of the Recipient

(1) Right of Equal Access to Programs:

The medical care system in Ontario is based on the principle of universal health care so that all patients have equal access to medical facilities. In the case of organ failure and the requirement for organ transplantation, there are a series of steps which the patient must proceed through in order to obtain service. Patients with kidney failure are introduced to dialysis which maintains their life. Their wish to have a transplant, as opposed to being treated by dialysis, is usually respected by the physican in charge of their care. They are then introduced to the transplant program and allowed to go on the transplant list unless there are medical problems that preclude this step. However, it became obvious in discussions with patients during this process of study that either patients frequently did not know they were on a transplant list or believed they were on a transplant list when they were not. Other patients had a view of transplantation which did not reflect current experience as they felt themselves to be ineligible for transplantation when in fact they were.

Therefore, theoretically the right of the patient to accurate information regarding available facilities is self-evident. Operatively, it becomes quite difficult in fact to ensure the accuracy and adequacy of information. Many programs that care for dialysis patients do not have direct interactions with transplant programs although all Ontario programs have links or arrangements of some sort with transplant programs. The geographical distances between centres make equitable access difficult to ensure. However, it was clearly expressed that an obligation exists to provide information to patients suffering from terminal organ failure regarding the right to be considered for kidney, heart or liver transplantation with the only constraints being the availability of hospital beds, physicians' and surgeons' time and, of course, donors. The profession has an obligation to verify that patients are obtaining accurate information and have reasonable access to the transplant programs.

There have been instances recently reported in Great Britain and the United States where it has been suggested that access to programs was based on the recipient's ability to pay or in some way reflected social standing. Therefore, safeguards must be placed in the system to prevent such occurrences. Such instances are more likely to occur in situations in which foreign citizens are admitted to Canadian programs. The rules that should govern admission of aliens to Canadian programs have not been established and therefore a potentially large problem may occur if, from the beginning, a priority is not given to Canadians in Canadian programs. On the surface this statement would appear to be unethical since the sickest patient should be the individual who gains access to the program. However, several of the largest countries in the East and near East prohibit, on religious grounds, the donation of cadaveric organs and consequently their constituents must travel to a Western program to obtain an organ. The sheer increase in demand that will occur if they are allowed to compete for places in our programs to the exclusion of Canadian citizens is an overwhelming ethical dilemma. The Transplantation Society's Ethics Committee and its Council recently deliberated on this dilemma and have issued a statement supporting the principle that first access be given to the citizens of the country within which the program exists.

(2) Right of Access to Donors:

Many of the principles enunciated under the equal access to programs applies to this area as well. However in a much more subtle way the rights of the recipient can be ignored without the recipient's awareness. If the recipient does not gain access to a program resulting from lack of referral or appointment then it is obvious that the recipient is not receiving equitable access to health care. However, once accepted into a program they are on a transplant list and presumably have equal opportunity to an available donor within their region. Decisions regarding organ distribution are frequently based on tissue typing or blood group analyses; however, medical urgency clearly takes precedence in many situations.

Other decisions made by the transplant physician or surgeon are open to a number of possibilities Does the recipient have the right to know when their blood is being cross-matched against the donor and the result of the outcome to that cross-match? Do they have the right to know the basis upon which the decision was made that the organ would not be transplanted into them? Is there a recipient advocate in the decision-making process who examines such issues? Are there situations in which program priorities take precedence over patient priorities regarding organ distribution? These are issues encompassing some profound ethical questions and yet, in general, the system has depended upon the good intent and wisdom of the physicians and surgeons who make such decisions.

Another issue of considerable importance frequently related to this program versus patient priority question is the criteria by which patients are placed on the active transplant recipient list. A general definition of suitable candiates would include age criteria, current and previous stability of the patient and his/her social support system, and the presence of other diseases which might reduce that individual's likelihood of success. All of these criteria for admission to a transplant list or program are based on the premise that one is attempting to achieve the best results possible with a limited resource; this being donor organs. Generally, this is a defensible arrangement which becomes indefensible on a case by case basis since from time to time organs may actually be in surplus (particularly relating to blood group A recipients). For example, does an individual who is 51 years old not have the right to a heart transplant whereas one who is 50 years old does? These issues were not addressed for resolution by the Task Force but are tabled as areas which require debate and eventual resolution must be reflected in policy of the transplant units in Ontario.

Who Owns The Organ?

Many of the dilemmae that surround transplantation focus on the question of "who owns the organ?" once it has been removed from the donor body. Does that organ belong to the surgeon who removed it or the physician who operates the program? Does the organ belong to the hospital in which the transplant program resides or to the regional retrieval and exchange group responsible for transplanting the patients in their region? Does the organ belong to the country and the citizens of that country in which the organ was removed or is it owned in a global sense by those pooled recipients who are waiting for a donor? The consensus seems to be that the physician or surgeon with the responsiblity for determining the destination retains that organ "in trust" for the general pool of considered recipients.

This potential group of recipients may be defined in a regional or national sense but it clearly is not within the realm of that physician/surgeon to trade the organ for anyone's advantage other than for the most logical group or pool of recipients. The Task Force did not pursue the question of the donor family and who they felt they were donating to and no known surveys have documented committed individuals as to the desired destination of their organs. However, recent articles in the popular press have revealed that organs recovered in one country were transported to another country with implications of financial gain to the retrieval group in the original country. It seems abundantly clear that this practice of providing tissue for national or international commerce was not the intention of the donor or donor family. Rather their sense of charity and beneficience was extended to individuals suffering from organ failure. The journey time between the donor and the recipient should be the shortest possible and the most efficient. This implies that anyone involved with the management or handling of organs and the logistics of distribution should be diligent in order that all retrievable organs are recovered and distributed to the nearest individual most in need. The organizational networks built around the retrieval of organs are dependent upon volume and certainly the success of a transplant program depends upon the adequacy of its organ retrieval system. The Transplant Society has clearly defined this system's role as a "sacred trust" and the rules and policies governing the distribution of these organs are ones that require standards and audit. The Task Force and the Conference addressed itself to the question of the audit of the transplanted organs and it is obvious that this is something that must be operationalized and then undergo a geninue period of review.

Commercialization

Transplantation has advanced from an endeavor that was largely experimental, in which the number of donor organs frequently exceeded the number of recipients on a waiting list, to one in which major clinical departments and hospital endeavors are dependent upon transplantation as a pivotal program. Efficiency varies tremendously from center to center both with respect to organ retrieval and organ transplantation. As a result, wide disparities in supply and demand occur with a resulting situation in which programs have excess organs while individuals in other locations, desperate for a transplant, become susceptible to a commercial endeavor. There was unanimity that profit should not be allowed within the transfer or transport of human organs nor should there be any direct or indirect profit to those individuals with decision-making power regarding an organ's destination.

The unfortunate precedent of the American experience of paying for blood donors was referred to frequently in discussions. However, this experience is a chapter in the history of medicine which is best remembered in order that it not be repeated rather than being a precedent allowing the sale of human tissue. The ethical arguments one might generate for allowing an individual to sell his or her tissue for gain are cogent and justifiable in isolated examples but the net negative effect of allowing organs or tissues to be sold for personal or corporate gain far out-weighs those considerations. A recent example in the popular press recounts the obtaining of live kidney and corneal donors in which exploitation of both the donor and the recipient occurred rather than the provision of benefit in a free enterprise mode. It is with these issues in mind that the Transplantation Society has issued guidelines for the practice of transplantation which avoids commercialization.

GUIDELINES FOR CADAVER ORGAN DISTRIBUTION

1. The best possible use must be made of the donor gift.
2. Organs should be transplanted to the most appropriate recipient on the basis of medical and immunological criteria.
3. Usable organs should never be wasted. In the majority of cases, an organ will be used within an established regional or national organ sharing network, and only if it cannot be placed should it be offered to other creditable networks.
4. Sharing of organs should only be arranged via national and/or regional organ sharing networks.
5. Priorities in the assignment of organs cannot be influenced by political considerations, gifts, or special payments or by favoritism to special groups.
6. Transplant surgeons/physicians should not advertise regionally, nationally, or internationally.

GUIDELINES FOR THE DONATION OF KIDNEYS BY UNRELATED LIVING DONORS

1. Living unrelated donors (ie. not first degree relatives) should be used exceptionally when a satisfactory cadaver or living related donor cannot be found.
2. It must be established by the patient and transplant team alike that the motives of the donor are altruistic and in the best interest of the recipient and not self-serving or for profit. In the best interests of all concerned, the motivation and medical suitability of the donor should be evaluated by physicians independently of the patient, physicians, and the transplant team. An independent donor advocate should be assigned to the unrelated donor to ensure that informed consent is made without pressure, to enhance personal attention given to the donor throughout the entire donation period, to ensure official expressions of gratitude and to aid with subsequent problems or difficulties. In all instances, and especially in the exceptional case where the emotionally related donor is not a spouse or second degree relative, the donor advocate would ensure and document that the donation was one of true altruism and not self-serving or for profit.
3. Active solicitation of living unrelated donors for profit is unacceptable.
4. Living unrelated donors must be of legal age.
5. The living unrelated donor must satisfy the same ethical, medical, and psychiatric criteria used in the selection of living related donors.
6. It should be clearly understood that no payment to the donor by the recipient can be allowed. However, reimbursement for loss of work earnings and any other expenses related to the donation is acceptable.

7. The diagnostic and operative procedures on the donor and recipient must be performed only in recognized institutions whose staff are experienced in living related and cadaveric transplantation. It would be expected that the donor advocate should be a member of the same institution but not a member of the transplant team.

SPECIAL RESOLUTION

No transplant surgeon/team shall be involved directly or indirectly in the buying or selling of organs/tissues or in any transplant activity aimed at commercial gain to himself/herself or an associated hospital or institute. Violation of these guidelines by any member of the Transplantation Society may be cause for expulsion from the Society. The Human Tissue Gift Act of 1972 precludes the sale of human organs. Good medical ethics require us to monitor transplantation and assure that commercialization does not occur.

References

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